THE VIRTUAL CUP OF COFFEE: NORTHERN CANCER PATIENTS' EXPERIENCE WITH SOCIAL WORK AND TELEHEALTH

by

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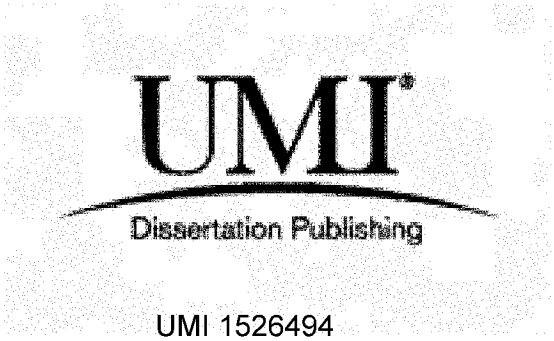

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Abstract

Social work in oncology addresses the distress experienced by people dealing with cancer. Residents of northern British Columbia have access to this service through Telehealth. Seven people, who were dealing with cancer, were individually interviewed using semi-structured, open ended questions about their experiences using social work through telehealth. The data was divided into textural and structural themes and analyzed through the writer's own experience with providing oncology social work and telehealth to over 500 people in Northern BC. The results are that some people with cancer 1) feel alone, 2) receive the service at inopportune times and 3) feel discomfort with it. However, once rapport was achieved through incorporating northern realities into the experience, participants felt the service was helpful and comfortable; and all would recommend it. Despite this, without the proper structural and system support, careful consideration should be made before this mode of oncology social work delivery is more widely used.

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Glossary of Terms

Oncology: The study and practice of treating cancerous tumors. It is often subdivided into medical, surgical and radiation oncology. (Werner – Lin & Biank, 2006)

Psychosocial Oncology: It is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer. (Canadian Association of Psychosocial Oncology, 2009)

Telehealth: Telehealth refers to the use of information and communication technology to deliver health care services, enterprise and information over long distances. (For the purpose of this paper, Telehealth is used - however, the words more relevant lie somewhat between tele-oncology and video-based technology.) (Institute of Health Economics, 2007)

Tele-oncology: Tele-oncology uses communication technology for provision of oncology services to eliminate or reduce geographic barriers for cancer patients and their families. (Institute of Health Economics, 2007)

Video-based Technology: Technology used for interactive audiovisual communications between patient and providers, patient and family (support network), or provider and provider, that allows timely access to specialist knowledge or enhancement of the plan of care. Videoconference is often used as a synonym for video-based technology. (Institute of Health Economics, 2007)

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I would like to thank my husband and my daughter as they are my motivation in life. I acknowledge the hard work and dedication of the Community Oncology Network staff in Northern Health because they provide the on-going care and compassion to people living with cancer in northern British Columbia. I thank the participants for their time and their willingness to allow me into their lives. I sincerely value and appreciate my thesis advisor for her patience and compassion during the completion of this process.

Chapter One: Introduction

Cancer. Think of this word. Ponder it for a moment. It is a powerful word. It conjures up images, memories, and for many strong emotions. Think of the statement: "You have cancer". Now think of living in a northern rural community of British Columbia, hundreds of kilometers from a cancer treatment center. It is undeniable that cancer is a distressing experience for people and for their families. This distress can have an exponentially greater impact for people living in northern communities than in southern communities due to the realities of northern living. People in the north often need to travel long distances for treatment, or have little access to specialized cancer care services.

In 2005, the Northern Health Authority (NHA) formed partnerships with the Province of British Columbia and the British Columbia Cancer Agency (BCCA) to address the complex issues associated with people experiencing cancer in northern British Columbia (BC). From this partnership, the Northern Cancer Control Strategy (NCCS) was formed. One of the objectives was to provide better cancer care service to residents of NHA; one way this was achieved was through access to specialized cancer care service through the use of Telehealth. The NCCS developed Telehealth systems as a way of communicating between cancer specialists (usually located in a centralized area) and cancer patients (located in one of the different community cancer clinics of the NHA). The specialist and patient interact with one another by looking and speaking into a television. They hear and see each other with clarity and in real time. Social work is one of the specialties of cancer care; it is often referred to as psychosocial oncology or oncology social work.

Rationale

Approximately five years ago, I began providing cancer patients in northern BC oncology social work service through Telehealth. The service was based out of Prince George and the cliental could be from any community in the NHA. Since that time, many rich and rewarding experiences come to my mind. One in particular resonates with me and has motivated me to look further into what are cancer patients' experiences using social work and Telehealth. I met with a woman (approximately 55 years old) for the first time through Telehealth. She had a diagnosis of pancreatic cancer, and the prognosis was that she was unlikely to survive more than three months. When I met her, she was not alone; her best friend since she was 15 years old sat in on the Telehealth session. The best friend had arrived from out of town and was in the patient's community for only a few days. I began the session by explaining the services. Then, I listened to lifelong friends talk and explore their feelings of knowing it may be their last visit together. After an hour long session, the patient requested to meet with me again during her next cancer treatment. I met with her two weeks later. At the following appointment, the patient's physical condition had visibly deteriorated; her skin was gray yet yellow and she had a gaunt look within her eyes and cheeks. At the end of the session, the patient said "Thank-you. I did not know what it was going to be like to meet with you, but after meeting with you, I feel like I have reconnected with a long lost friend over a cup of coffee. You have asked me questions that I didn't know that I needed to ask myself, like only an old friend would." This memory has profoundly impacted me, and has led me to my present research, "The virtual cup of coffee: Northern cancer patients' experience with social work and Telehealth."

Over the last five years, I have been witness to and involved with practicing oncology social work through Telehealth to cancer patients of the NHA. I have interacted with cancer patients and their support units over 500 times through Telehealth. Within my experience many turbulent, dynamic, troublesome and endearing stories come to my mind. There are many people and families whose stories stay with me and guide my present practice and my drive to complete this research study.

As a person born and raised in Northern British Columbia, and as a professional practicing social work in a northern health care setting for almost fifteen years, the role of providing psychosocial oncology to the entire NHA via Telehealth has intrigued me and perplexed me. I practice from a northern social work perspective. This perspective is one in which the social worker recognizes the unique needs, dynamics, and ebbs and flows of every northern community (Schmidt, 2009). There are nine community oncology clinics within NHA where social work Telehealth service is available, yet the cancer patients attending these clinics can come from numerous communities around them, and each of these communities have their own identity. Unfortunately, this identity is not always easy to recognize or acknowledge by others. A northern social worker is aware that northern communities can come from a culture of opposition (Zapf, 2002). Northern communities often have had to conform and abide to southern political climates and ideologies that often do little to recognize the northern way of being or functioning. Perhaps, the structure of the system in which one social worker providing service to all cancer patients in northern BC based in a more southern northern BC location preserves the status quo of northern communities abiding by southern solutions. Only through a northern social work practice

viewpoint, can this southern ideological political cultural system be weakened when working with cancer patients.

My northern social work perspective guides my oncology social work practice. Psychosocial oncology, oncology social work, cancer care social work all are essentially the same. They are concerned with providing specialized service through information, support, counseling, referrals, and advocacy. They strive to lower distress for cancer patients and their support systems in order to improve cancer treatment outcomes and overall quality of life for both the patient and their support systems (Andersen, 1992; Iacovino & Reesor, 1997; and Zabora, Brintzenhofeszoc, Curbow, Kooker, & Piantadosi, 2001). This type of social work is eclectic in its approaches, focusing on the individual needs of the patients and their families rather than on a specific mode of delivery (Holland et al., 2010). Over the last five years, I have gained knowledge and skills, learning about the specialized issues that cancer patients face both in terms of psychological and practice matters. Blending northern social work practice with oncology continues to be perplexing and intriguing, even more so given that this service and intervention is provided through Telehealth.

Telehealth, as supported by the Northern Cancer Control Strategy, is the preferred means of delivery of specialized psychosocial care to cancer patients within the NHA. Five years ago as a social worker with little knowledge of Telehealth, I was eager to learn, practice, and create my skill base to provide this service effectively. I began to recognize little nuances in my practice that were different than that of my direct face-to-face delivery. For example with Telehealth, I found myself taking more time to build rapport with cancer patients. This was perhaps due to my wish to make myself more comfortable for the client. I also recognized that at times, I would become somewhat of a clown by providing big over-

exaggerated facial expressions. I would acknowledge the strangeness, yet point out the modernity of Telehealth approach. "Now you can tell your grandson that you are up with technology; you even tried something better than Skype." Silences were more pronounced, and I had to learn how to be more comfortable with the natural more noticeable pauses of conversations. As a northern social worker, I readily acknowledged issues that were unique to the northern communities. For example, one community had a large turnover of medical staff. When a person is dealing with a potentially life threatening illness, change over in staff can often lead to lack of confidence in the stability of treatment and therefore outcomes of treatment. Understanding this, as well as understanding the contextual importance for a person living in northern BC communities, I acknowledged the fear of turnover to the patient yet highlighted the special qualities of the north and that community specifically.

As I discovered the nuances in my practice, I searched for literature and information to increase my skills and understandings of these Telehealth practice nuances. Unfortunately, although perhaps one could say an array of literature exists on tele–services (psychology, psychiatry, oncology, psychosocial), little information was discovered on the use of Telehealth with social work service for northern recipients dealing with medical situations. Although the literature outlined that cancer patients found Telehealth service beneficial and satisfactory, no specific information was discovered about *why* cancer patients found it satisfactory, and *what* if anything the professional did to make it beneficial or not.

Research Question and Objective of the Study

This research study looked at how the social work specialty of oncology attempts to meet the psychosocial needs of cancer patients in northern BC through Telehealth. I am a social worker providing this specialized service and I believe it is necessary to understand how cancer patients perceive this service. The study focused on cancer patients' experience receiving social work service by Telehealth. Through the use of phenomenological research, the following two questions are addressed: 1) What was the northern BC cancer patients' experience using Telehealth service from a social worker? 2) How should social workers provide service to cancer patients via Telehealth in northern BC? The information obtained in this research study may be useful as a guide to inform social workers providing Telehealth service for cancer patients in northern BC on best practices.

Case Examples

It is important for my professional practice that learning and research is meaningful; it needs to provide me with a way in which I can relate the learning to the people that I serve. Given this, I often find myself identifying information into phenomenon. For the purposes of this study, I find that outlining three fictitious case examples is useful. Although these case examples are not completely real, they draw upon my work experience of over 500 cases. Many elements are true and they resemble many situations.

Case Example #1 - Jo

I recall one particular time in which I was asked to help with an Aboriginal cancer patient, "Jo" and his wife through Telehealth service. I was told that he was in hospital; he was in a wheelchair due to limited strength and mobility; and that he was wanting to talk

about cancer to someone who would listen. The referral came from the chemotherapy nurse, who warned me "he is very angry as he thinks that he is not being told the truth". It is important to note that within his home community, there are no social workers trained in psychosocial oncology. He was also an inpatient in a hospital that was over 800 km away from my location.

I met with Jo, his wife and the Aboriginal Patient Liaison Worker the following day. It was not particularly difficult for Jo to meet with me, as his wife took him in his wheel chair from his hospital bed down the hallway to the Telehealth room. Upon beginning, I explained what I do, how the Telehealth system worked, and where I came from. As we began our conversation, I asked a few of the principle questions of social work intervention: who was he and his wife, what was their understanding of why he was in the hospital, and who was his support. The answers to these questions did not appear to come easy for him nor his wife. He started to raise his voice and making comments like "why am I here", "you can't help at all", "this is a waste of time". I realized that I needed to be careful with my wording and truly listen to both him and his wife. They mentioned that there were struggles with his diagnosis and prognosis (terminal pancreatic cancer); that their children were acting up; and that all he wanted to do was go home. Unfortunately, his home was not accessible by a wheel chair. I listened to their concerns and started to provide information about children's responses to a sick parent. At this point, Jo attempted to leave the room in his wheelchair while getting caught up in the other furniture. He broke down crying, and his wife and the aboriginal worker soothed him by patting his back. He agreed to stay if we did not talk about his children.

The conversation continued. I provided information about processes for diagnosis and treatment within NHA, and affirmed to him the time frame in which he received treatment was the normal time frame throughout northern BC. I confirmed with him that I would advocate for him with income assistance about helping to fund a new damage deposit for a new rental location as he desperately wanted to return to a home so he would not die in the hospital. Finally, I listened to his fears and frustrations about his disease and his worries about leaving his family behind. At the end of our meeting, Jo told a couple of jokes and we laughed together. His wife and he thanked me for my time. One week later, Jo died in the hospital.

Case Example #2 - Alice

Alice was a 56 year old woman, who had metastatic lung cancer. I was asked to meet with her through Telehealth, by a chemotherapy nurse in a northern BC community. The reason for the referral was that Alice was feeling depressed and wanted to talk about this. Her family doctor prescribed Alice with anti-depressants the day before the referral, but she reported to the nurse that she doesn't feel satisfied with this solution and that she believes she is going crazy.

I met with Alice and her husband through Telehealth. Alice promptly started to cry and her husband looked at her with hopelessness in his eyes. I asked her for the reason why she was crying. Her answer was because "I won't get to drive my grandkids to hockey practice anymore." Her husband spoke up and said that he would be able to. This dialogue continued, and I discovered that Alice's raison d'etre is to spend time with her grandchildren

and care for them which involved driving them to activities. She was told that the anti-depressant would impair her ability to drive.

Upon further exploration and assessment of the situation, I learned that six weeks earlier, her family doctor told her and her husband to "get her affairs in order" as it is likely she will not live for more than six more months. This prompted them to take a month long honeymoon, which they never had, to Hawaii. She returned one week previous to our meeting and stated that since returning, she felt like a large jail cell door had just been slammed shut. I learned that she cried mostly when she thought of her grandchildren and how hard her death will be on them, that she struggled with being a future burden on her husband, and that finally it was difficult for her to watch others do the work she normally would have done (cook or clean). Further information was obtained and it was clear that Alice was grieving.

I spoke with Alice about the grief and loss issues that terminal cancer patients encounter and that many cancer patients identify with this more so than with a diagnosis of depression. I informed her about the normalcy of grief and to recognize the various ways it is displayed in actions, emotions and thoughts. I encouraged her to go back to her family physician and explore the idea that maybe she might be grieving and not be clinically depressed. I provided a reference for her and her family to read about the dying process. After gaining her permission, I called her family doctor and spoke with him about my observations. He agreed that perhaps antidepressants may not be the best form of intervention.

One month later, I met with both of them again. She spoke of the continued grief she felt but did not feel crazy and realized she was normal. She decided not to take the antidepressants and was able to continue to drive her grandchildren to their activities.

Case Example #3 - Al

One afternoon, I was asked to see a man through video link despite the man being bedridden in the hospital. After arrangements with the hospital staff, they managed to wheel his bed into a Telehealth room in order to help support him and his family. The reason for the referral was that he had been receiving months of chemotherapy without success and was just recently placed on the palliative care program. He and his family were very angry and the family was in shock that there would be no more chemotherapy. It was suspected that he did not have many days to live.

I dialed into the Telehealth room. There were two young adults sitting next to him, and his wife was standing. Everyone was quiet and subdued. The patient asked in a raspy voice "do I call my daughter home." (His daughter had just left the home community to travel to Europe on a three month vacation. Incidentally, my experience is that it is very common that young adult children will go and travel when a parent is so close to death). At the same moment one young adult said "I don't know what to do." As delicately as possible, I spoke to the family about the consequences of either calling the daughter or not. To address the young adult's question, I suggested that each of the children say the things that they want to say to their father, the reasons the love him, the memories they have, and the lessons that he has taught them. I encouraged them to maybe even do this in the form of a letter.

The mood was somber and I did not spend much more time. I hoped that I helped through speaking of the unthinkable and unmentionable, and allowing them to consider the ways to deal with it. I said some difficult things for the family to hear in this brief intervention: i.e. not waiting until a better time as my experience is that there usually never is a better time.

I did not see the family again and a few days later the patient died.

Many months later, a new acquaintance found out that I was a northern health social worker who worked with cancer patients. Her partner was Al's son. She did not appear to realize that I had worked with her partner's family. She passed along a story of how one day when her father-in-law was first brought into the hospital a social worker came and saw the family. Her partner called her after. He was very mad, and stated "How dare that social worker tell our family what to do – and tell me how to talk to my father!" She said she was glad that the social worker talked to them though because the family did call the daughter back. More importantly she said her partner would have never written a letter to his father, but he did write a letter to his dad, he did read it to him, and they did say "I love you" for the first time, shortly before Al died.

Chapter Two: Literature Review

Cancer & Distress

Canada is a country in which individuals and families are affected daily by cancer. For example, it was estimated that more than 187, 600 people were diagnosed with cancer in Canada in 2013; which was an increase of almost 10% since 2010. Additionally, approximately 75,000 people died in 2013 year from cancer (Canadian Cancer Society, 2013). The rising pattern of statistics for the Northern Health Authority in British Columbia is no different. In 2005 it was estimated that about 8,000 people in northern BC were living with some form of cancer but by the year 2015, the estimate of people living with cancer will have grown to about 11,000 people (Jago, 2006).

One can naturally assume that with a cancer diagnosis, comes distress. Distress is defined as

> a multifactor unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis (National Comprehensive Cancer Network, 2008, p.5).

The distress associated with cancer and its treatment can cause significant psychological responses within individuals. One only has to imagine the ways in which cancer can ravage the body in order to understand this. Studies demonstrate that between 25%-50% of individuals will have psychological problems and at least 25% will meet the criteria for

major depressive disorder or adjustment disorder (Hopwood & Stephens, 2000; Massie & Holland, 1990; Sellick & Crooks, 1999). Distress can have major consequences for an individual's quality of life (QOL), cancer treatment outcomes, and overall well-being (Meyer & Mark, 1995). When patients experience distress, QOL decreases; when distress is alleviated, QOL improves (Hopko & Lejuez, 2007). "Patients whose psychological needs are met are better able to cope with their diagnoses and treatment, have better physical functioning, greater quality of life and less utilization of medical services" (Kash, Rajinish,& Kunkel; 2005, p.213). White et al. (2011) completed an unmet psychological and practical needs study of cancer patients in rural and remote areas of Western Australia. The results mirror previous research of cancer patients within different geographic and population bases. This is that regardless of where one lives, cancer patients have significant distress as well as practical and psychological needs (White et al., 2011).

Barrier to Access Social Work Services

The medical setting can impede cancer patients' ability to address the distress associated with cancer and its treatment. The primary role of the medical setting is to address the physical treatment of cancer; however, the secondary role is the treatment of the psychosocial distress associated with cancer (Siegel, 1990). Medical professionals need to attend to the secondary role of treatment. A cancer patient and their loved ones come to implicitly trust, interact, and rely upon professionals to treat the cancer. Medical professionals' willingness and openness in addressing the psychosocial needs can strongly influence the cancer patient and their loved ones in acknowledging and recognizing the secondary role of treatment: attending to the psychosocial distress of the disease (Pray, 1991). Several studies have shown that oncologists are not especially skilled at discussing

psychosocial problems, or recognizing anxiety and depression. (Ford et al, 1994; Hardman et al, 1989; Newell at al., 1998; Passik et al, 1998). Pray (1991) in a survey of physicians treating hospitalized patients found that although 90% of the practitioners were able to identify emotionally laden medical conditions, only 41% of them made referrals to social workers. Disappointing, but not surprising, was that social work referrals were made for problems typically associated with discharge planning and not psychosocial distress associated with cancer. Unfortunately, at times medical professionals do not always openly discuss distress or recognize the symptoms of distress in cancer patients. "Most published data suggest that the doctor's ability to accurately detect psychosocial morbidity in cancer patients is often little better than due to chance" (Fallowfield et al., 2001, p.1011). Eakin and Strycker (2001) assessed the barriers to using psychosocial support and information for cancer patients. They found that patients did not access service because of the lack of referrals from service providers. Literature findings point to the importance of provider referrals to and endorsements of cancer support services.

In northern and rural settings, medical professionals attuned to the psychosocial distress of their patients, do not have the tools, resources or time to address the complex needs of their patients. Fedorchuck et al. (2003) explain:

> There is a need to address quality of life issues more frequently and increase patient education to empower decision making. Unfortunately however, in a community setting such programs and social services are usually provided only to people who either demand them or are unmistakably in distress (p.36).

In fact, when one looks at the case examples, all participants were referred to the social worker later on in the journey when it was obvious that the clients were in distress.

Shepherd et al. (2006) explain that in rural and remote communities, if psychological problems are detected for cancer patients, it is generally the nurse or general practitioner whom responds to these problems in an informal way. A referral is not made to a psychosocial professional and the way in which the distress is addressed is often not adhering to best practice standards. Unfortunately, this has been my experience in some cases. I have situations where, by chance, either a family member in distress has searched out my service, or an alternative agency or concerned citizen has asked for my involvement to assist a patient or family. Usually when this happens, the patient and family have not had service such as psychosocial oncology counseling nor information and resources for support; and their distress level is elevated.

Cancer patients in northern BC may have needs that could be addressed by an oncology social worker; however, this may depend upon whether the medical setting provides this referral. Furthermore, this may be challenging for those medical professionals unclear of or uncomfortable with the use of Telehealth.

Northern Cancer Control Strategy

In 2005, the Northern Health Authority (NHA), the British Columbia Cancer Agency (BCCA) and the Ministry of Health for British Columbia developed a comprehensive cancer control strategy: the Northern Cancer Control Strategy (NCCS). The strategy was developed through extensive consultation with community members and health care providers in order

to provide better cancer care services to patients, families and communities throughout the cancer care continuum. Jago (2006) clarifies that

> What has become clear to us during this process is that British Columbia has a cancer care system that, while of the highest quality, is difficult for Northerners to access without encountering significant obstacles of distance, time and personal expense (p.ii).

According to Jago (2006), the NCCS "responds to the epidemiology of cancer in the North and the demographic and service delivery challenges that are unique to northern BC" (p.3).

The NCCS focuses on three major pillars that are relevant to cancer treatment along the continuum of cancer care (from prevention through to diagnosis through to treatment to rehabilitation). These pillars are 1) Incidence of cancer, 2) Survival from cancer, and 3) Quality of life and access to services for Northerners (Northern Cancer Control Strategy, 2006). The third pillar attempts to address the issues of great geographic distances of NHA (appendix A), limited population numbers and a small human resource base. In order to address these issues, the NCCS developed comprehensive Telehealth services including the infrastructure, equipment, and human resources to manage it. It is used within each of the nine community oncology clinics in northern British Columbia (BC). (Appendix B). Through the use of Telehealth, patients and families in northern BC have access to specialized resources that would not normally be available to them. Oncology social work is one of the specialized resources and access to it may provide an avenue to lower the distress associated with having cancer.

Many of these community oncology clinics had no previous or very little access to a medical or health care social worker. The idea of a regional urban-based social worker may not be viewed as something useful or needed despite the social worker being accessible to the

community. As Collier (2006) notes "social workers should not expect to be automatically awarded a friendly reception simply because they align themselves with the community" (p.50). Community members or health care professionals from the community oncology clinics may be reluctant to engage with a person not living within their community. Further, the NHA regional based oncology social worker, myself, is based in a possibly perceived urban southern center, Prince George; and the service may be viewed as an imposition upon the northern communities. "When service decisions are made at senior political and managerial levels in the urban centre, the resulting services are unresponsive to the users, and ultimately unrewarding places for community social workers to work" (Isaac & Stokes, 2009, p. 179). The NCCS attempts to provide access to specialized cancer care, from a centralized base, to northern communities through Telehealth; but, it may not be perceived by northern communities as a welcome or beneficial service.

Oncology Social Work

Social workers provide a wide range of service to diverse populations in a variety of formats. Social workers provide counselling, education, advocacy, and referral services to agencies for individuals, families, groups, and organizations. The people social workers provide this service for could include children, the elderly, immigrants, individuals with addiction challenges, people who are adjusting to difficult life events and those who live with a life threatening illness such as cancer. Oncology social workers work with cancer patients and a wide range of issues; often this form of practice is called psychosocial oncology.

Psychosocial oncology

> is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality – of – life and functional aspects of cancer, from prevention through bereavement. It is a whole – person approach to cancer care that addresses a range of very human needs that can improve quality of life for people affected by cancer (Canadian Association of Psychosocial Oncology, 2009).

Fedoruchuck et al. (2003) inform us that cancer patients require support from psychosocial oncology professionals as cancer patients may not have it amongst their intimate connections, they have difficulty coping and finally they need advocacy with financial assistance. Werner–Lin and Biank (2006) assert that

> Social workers with specialized knowledge in psycho-oncology are familiar with the challenges specific to varied types of cancer diagnosis and are skillful at delivering interventions that address the adaptive and psychosocial needs of clients during the different stages of illness development (p. 508).

Miller (2007) argues that social workers who specialize in cancer care are better able to deal with the complex needs and issues of people experiencing cancer than those who do not have a cancer care background. "Cancer patients who require psychosocial oncology intervention need to be provided this service from a social worker trained, educated and aware of the impact of cancer specifically on the lives of the individual" (Kash, et al., 1999).Oncology social work has become a specialized field of practice with informed and effective methods of working with cancer patients and their families (Stearns, Lauria, Hermann, & Fogelberg, 1993). It provides psychosocial assistance to cancer patients and their support unit throughout the cancer journey: at time of diagnosis, during treatment, after treatment is

completed, upon a re-occurrence, and when treatment changes from cure to palliative (Spiegel, 1990; Werner-Lin & Biank, 2006 & White, 2011) According to Zebrack, Walsh, Burg, Maramaldi, & Lim (2008)

> Oncology social workers participate on multidisciplinary teams in cancer centers and community hospitals and sometimes in oncology group practices. Some obligate all their time to oncology services, others rotate through oncology as well as other medical services (p. 356).

Regardless of the workplace setting, he or she aims to address the distress that is associated with cancer and its negative implications associated in any phase or stage (which is often associated with prognosis) of the cancer journey. Fedorchuck et al. (2003) looked at prognosis of individuals and their perceived coping, support, and need for financial assistance. The study concluded that amongst all prognosis of individuals from dismal to excellent, people required further support. Fedorchuck et al. (2003) explained that

> More than 10% of patients with a good or excellent diagnosis had difficulty coping emphasizing the fact that patients with a good prognosis are not exempt from the ravaging emotional and social consequences of their disease (p. 31).

Thus the social work specialty of oncology may be needed for not only patients with a poor prognosis but also for people in all phases of the cancer journey.

Psychosocial oncology intervention occurs with cancer patients at various stages in their illness journey. Common psychosocial features are reflected in each stage of the journey. For example, a new diagnosis has patients and families faced with making critical treatment decisions amongst a time when they are learning and emerged within a new system

with a new language (Werner-Lin & Biank, 2006). At this time the social worker can help patients understand the medical system, translate medical language, and explore with patients and families values, beliefs and concerns about cancer treatment (Werner-Lin & Biank, 2006). The way in which the help is provided to a patient in a newly diagnosis stage is different than after a patient has been on treatment for several month. After several months of treatment, the patient may need help with finding solutions to the debilitating effects the treatment has on energy levels and physical strength (Werner-Lin & Biank, 2006).

Zebrack et al., (2008) explain that the literature on the practice of oncology social work outline direct tasks

> as being (1) screening and psychosocial assessment; (2) facilitating adjustment to illness; (3) provision of counseling and individual, family, and group psychotherapy; (4|) discharge planning; (5) referral; (6) advocacy (357).

Zebrack et al., (2008) further argue that the tasks must be provided where needs are most acute and in a manner that is appropriate and fluctuant to diverse populations. Common tasks are to facilitate communication amongst family members and friends with the cancer patient and to provide psychosocial education (Kash et al, 1999; Siegel, 1990, & Zebrack et al., 2008). Often people with cancer are bombarded with remarks of being positive or of a problem free environment. Despite the good intentions of family members and friends, this will inadvertently isolate and disempower patients (Siegel, 1990). It has been my working experience that people who experience the tyranny of positive thinking express feeling isolated with negative emotions and unable to express them freely. I provide a venue for the cancer patient to express all emotions and to inform all involved that the cancer need not impact all aspects of their lives.

There are several types of studies assessing intervention effectiveness to adjustment and adaptation to cancer and to the ways psychosocial oncology is conducted. Iacovino and Ressor (1997) classify these studies into descriptive, quasi-experimental, retrospective and controlled clinical trials. Regardless of their classification, "no particular intervention appears to be significantly more effective than others in helping patients deal with cancer" (Iacovino & Ressor, 1997, p. 68). Meyer and Mark (1995) conducted a meta-analysis study to determine the efficacy of psychosocial intervention for cancer patients. After examining over sixty-two studies, Meyer and Mark (1995) concluded that it would be inefficient use of resources to conduct more studies addressing the question: "Is there an effect of behavioral, educational, social support, and non-behavioral counseling and therapy interventions on the emotional adjustment, functional adjustment and treatment related and disease related symptoms of cancer patients?" This is because all types of psychosocial interventions have a consistent beneficial effect on emotional and functional adjustment and on negative quality of life symptoms related to cancer and its treatment (Meyer & Mark, 1995, p.106).

Oncology social workers provide interventions that deal with practical matters to existential issues with a variety of approaches. Regardless, the literature points to the benefits this service has with assisting, helping or supporting cancer patients and it can be transferable to any setting or community including northern, rural or remote settings.

Northern Social Work Practice

Defining the concept of the north can include geography, history, economy, politics, and culture (Schmidt, 2008). Schmidt (2009) highlights common elements of north as being remoteness and isolation, relatively severe climate, sparse populations, limited services, transportation challenges, and economies dependent on single industries and resources.

Schmidt and Klein (2004) define a northern community as being above the 54th parallel, as being located more than a two hour drive from an urban center, as having predominantly a single-resource economy or a one industry community, and as having promotional material which identifies it as being north. For the purposes of this research, communities are within the Northern Health Authority (NHA) catchment area and are part of the NCCS community oncology clinics. Both NHA and the NCCS promote a northern service (see Appendices A and B). NHA community oncology clinics generally are one resource communities, identify themselves as being northerners, are located above the 54th parallel, and most are located greater than a two hour drive from the regional hospital center in Prince George which is considered more of an urban center.

Northern Canadian social work practice is difficult to define given the multitude of definitions for north and the variety of northern communities. A definition is not entirely necessary if one has an awareness of common influences on northern practice. These influences are physical space, climate, economy, social context, and the specific unique northern environment of each community (Schmidt, 2009). For example, a social worker in the winter may need to plan a support group during a weekend as opposed to a weekday evening because it becomes dark at 4:00 pm and if it is snowing the road conditions could become more difficult to navigate in the darkness. As well, participants of the support group may be driving longer distances to access the group, which is a reflection of physical space. Northern social work "appreciates the unique nature of each environmental context and never assumes that what is true in one context applies to another" (McKee & Delaney, 2009, p. 57). Not all the communities experience the same influences of north as other communities. In order to understand this, social workers in the north need to practice contextually.

Geography is a contextual component with northern social work practice. It is a vitally important practice ideology (Schmidt, 2009). Zapf (2002) outlines geography to include: demographic, political, economic, cultural, and phenomenological Demographic geography recognizes that a population figure of less than 10,000 (< 10,000) is considered rural, and a population figure of greater than 10,000 (> 10,000) is considered urban. Of particular importance for social work is that natural helping systems usually are seen with communities of <10,000 people. In communities with > 10,000 people, members within the community tend to rely more upon formal helping systems (Zapf, 2002). As an oncology social worker practicing in the north, I should be cognizant of this, as some of the community oncology clinics are based within communities of < 10,000 people whereas other communities have higher populations. For example, a family consisting of a young father, mother and three children from the community of Vanderhoof (<10,000) may rely upon the informal network of family and friends to look after the children if the mother or father needs to leave the community for six weeks of cancer treatment that is not offered locally. With a similar situation, but the family comes from Fort St. John (>10,000), the family may look towards the formal systems to support them such as non-profit societies or provincial services. Demographics within northern BC may then influence how and if social work service is utilized.

Political geography is how a province enacts its political platform. This often poses problems for service delivery to the north (Zapf, 2002). Human service delivery for the north is often formed by politics from urban, southern settings and the control for the delivery of service is held there as well (Zapf, 2002). Isaac and Stokes (2009) explain

> When service decisions are made at senior political and managerial levels in the urban centre, the resulting services are unresponsive to the users, inaccessible, inflexible, unresponsive to diversity, alienating to users, and ultimately unrewarding places for community social workers to work (p. 179).

One can see how political geography is influential when working as a social worker in northern settings. Economic geography is a relational aspect between north and south; whereas, the south makes economic decisions for the north and the north provides the geographic resources (Zapf, 2002). Many northern communities are one-industry communities and it is usually a resource based commodity. The industry is linked with economic geography. The global economy and its determination of the price of the commodity greatly influences whether the community members have jobs, have value within their homes, and have opportunities (Schmidt, 2009). Cultural geography is an ideological framework and world-view of living and being. Phenomenological geography is the way in which people from a specific geographic place prescribe meaning from their environmental experiences (Zapf, 2002).Cultural and phenomenological geography are equally as important as demographic, political, and economic geography to northern social work practice. However, these geographic concepts may be more difficult for social workers practicing within the north to understand especially if they are not from the north. Halverson, Brownlee and Delaney (2009) state

> Many social workers who come to the north from the south are dominated by southern metaphors which view the north as hinterland and so internalize a social work practice or political ideology that is southern-metaphor dominated (p 138).

Integrating geographic concepts of demographics, politics, economics, culture and phenomenology are essential contextual elements for a social worker practicing in northern BC.

Northern Canadian social work practice is different from other forms of social work practice (Schmidt, 2009). The differences may not be exceptional on their own, but, collectively, they provide a unique way to approach social work. Schmidt (2009) identifies five areas of practice which make it unique: northern travel; community rhythm; role conflict and community microscope; sense of community; and, opportunities of northern practice. For example, as a northern oncology social worker, I may be cognizant that a cancer patient is required to travel through a treacherous isolated dark mountain pass to come to the regional based hospital to meet with the oncologist. Within a large urban setting, a cancer patient may have to travel the same distance but on a double lane well lit and maintained, well-populated highway; where it is undeniably less stressful to arrive to the medical appointment. Another example demonstrates both role conflict and community microscope. I may simultaneously providing support with sisters-in-laws who have cancer and who are being treated in the same community. If one sister-in-law wants information about the other, the social worker must retain confidentiality and cannot disclose this nor even reflect an involvement with the other sister in law. However, due to the small community (i.e. community microscope), they may both be suspicious of social work involvement. The code of ethics for social workers in British Columbia state:

> A social worker shall protect the confidentiality of all professionally acquired information by disclosing such information only when required or allowed by law to do so or when clients have consented to disclosure. (BC College of Social

Workers).

Confidentiality is a complex issue for northern social work practitioners. Revisiting the earlier example of the sisters-in-law, further difficulties could arise due to role conflict. One sister-in-law will not see the social worker and thus receive no social worker intervention, if that social worker is perceived to be involved with the other. This is an excellent example of an issue that would likely not be encountered by a social worker in urban practice. As evidenced by Collier (2006):

> The categories of social problems defined by the specialist practice of urban social work do not reflect the conditions in rural regions. Many rural problems just do not break down that way and are interconnected with other problems and issues (p.37).

The combined areas of practice which northern social workers encounter are unique and different than that of southern, urban-based social workers.

Zapf (2002) highlights a major theme that emerges when acknowledging social work in a northern context: the "culture of opposition." The culture of opposition refers to how northern social work practitioners are often pressured to live, work, and practice under the dominant and influential ideologies related to southern/urban settings, settings which often fails to recognize the reality of northern social work practitioners. Isaac and Stokes (2009) comment

> When centralized, bureaucratic models of service delivery are imposed on small northern communities, they neglect the community culture. This results in less than optimum service for northern communities, and feelings of powerlessness, frustration and alienation for northern practitioners (p. 179).

With regard to my social work practice within the NHA, the culture of opposition may exist as the residents and health care professionals of the community oncology clinics may view the position of that as one from the south; and I will then practice in an urban way. Doll, Stephen and Poon (2004) asked healthcare professionals across Canada about the benefits and drawbacks to using Telehealth service: "A few key informants spoke of the importance of not using technology as an excuse to decrease care in rural communities" (Doll et al., 2004, p.18). Furthermore, this southern urban-based position may be viewed as taking away from the northern community and thus members may be opposed to its service. Although northern communities now have access to psychosocial care, it may be seen as way to limit services within the north which may be a real barrier to providing service. The culture of opposition is yet another unique feature of practicing social work in the North, and could have a potential negative impact upon a regionalized social work position. Therefore it is essential that a northern, rural, remote social worker, such as myself, remain cognizant of this dichotomy when working with cancer patients in the north.

A social worker providing northern services has access to large amounts of information. Harker (2002) interviewed northern rural health care workers to determine strengths and weakness of discharge planning in rural and remote communities. Harker (2002) commented that the physicians and nurses interviewed believe that the informal relationships that exist both between the medical staff and with the patients allow for a thorough and accurate assessment of the problem. Northern social work practice can provide a context in which the informal relationships build on richer assessments. For example, a social worker in a rural, small northern town could live proximally (such as on the same street) with a client and that they also interact with on a professional level. This is unique and

different from social work in an urban setting. "It is much easier to make a decision with certainty and confidence in a small community as opposed to a large urban center where it is not easy to gather information to make an accurate assessment" (Schmidt, 2009, p. 13). This capacity to assess the problem is a key and noteworthy aspect of social work intervention because intervention is based upon problem identification and assessment (Johnson &Yanca, 2007; Miley, O'Melia & DuBois, 1995). Vast amounts of information may also pose a challenge. When social workers are required to make assessments they need to distinguish between information gathered in a professional capacity versus personal interactions. For example, a social worker living in a northern community may have children who are friends with a client's children. The social worker's children may tell the social worker information about the client as they play at the client's house. Due to the information being learned in a non-professional capacity, the challenge is: how does the social worker bring this information into the client/social worker interaction? Northern social workers "need to come to terms with challenges that arise from high visibility, accessibility, access to too much information, and negotiating the pitfalls of multiple relationships" (Schmidt, 2009, p.15).The excess of client information can be further multiplied when nurses who are involved with making the referral, may also be experiencing a duality of roles with the cancer patient. Despite this potential challenge, within my regionalized position, I may experience less conflict with regards to access to too much information as the position does not place me living within the community, only working with the community members through Telehealth service.

Pugh (2006, as cited in Schmidt) points out that social workers in small communities are highly visible; and that it is difficult to not only keep a low profile and be anonymous but also it is easy to be scrutinized and judged by character and behavior. Schmidt and Klien (2004) state that "in a large center the relative anonymity of workers may not expose them to

the same level of personal blame that occurs in small isolated northern communities" (p.241). This is an essential point when examining the role of specialized oncology social work from a regionalized setting. As the social worker engages and works with families and healthcare professionals within the individual remote community, there may be an exponential amount of pressure upon him or her because he or she is the only available resource. Generally, the social work role in a small northern community is one that is unique and likely highly visible within a smaller community setting unlike that of larger urban setting. "People who receive social work service in rural areas generally have an opportunity to appraise and assess their social worker in ways that urban recipients of social work service cannot easily do" (Schmidt, 2009, p.12). Individuals living in smaller communities generally are aware of other people's problems and situations; this includes when a person is undergoing cancer treatment. The way in which the social worker provides service and support to one individual will be evaluated on multiple levels in the community (Isaac & Stokes, 2009). I work under a microscope meaning that I may be evaluated at all levels when practicing social work to people in the north impacted by cancer.

Generalist Social Work Practice

Generalist social work is a practice approach that takes on many definitions and forms. Miley, O'Melia, and DuBois (1995) define it as "the interplay of personal and collective issues and works with a variety of human systems – societies, communities, neighborhoods, complex organizations, formal groups, informal groups, families and individuals – to create changes maximizing social functioning" (p. 10). Marlow (2005) defines generalist social work practice as "a form of social work practice taught in B.S.W. programs that involves practice with different-size client systems and uses a number of

different interventions and practice roles" (p. 335). Johnston and Yanca (2007) define generalist social work practice as

> Practice in which the client and worker together assess the need in all of its complexity and develop a plan for responding to that need. A strategy is chosen from a repertoire of responses appropriate for work with individuals, families, groups, agencies, and communities. The unit of attention is chosen by considering the system needing to be changed. The plan is carried out and evaluated (p. 458).

There are a variety of approaches or models used with generalist social work practice. Timberlake, Zajicek-Farber and Sabatino (2008) argue for a strength based problem solving approach as a method of generalist social work practice. Tolson, Reid and Garvin (2003) believe that "mastering one practice approach, task centered approach, that has been applied across systems and with a large array of clients and problems, produces competent generalist social work practitioners" (p.2). Johnston and Yanca (2007) outline twenty - two models in generalist practice and this includes psychosocial, behavior therapy, and cognitive therapy.

There are commonalities of generalist social work despite the varying focuses of approaches. These commonalities are explained as a perspective which includes an eclectic base of practice, a multi-method approach, a focus on social justice and finally a process which includes an assessment, intervention and evaluation (Derezotes, 2000; Payne, 1991). "While generalist practice suggests a wholeness in which the social worker may shift from method to method, from strategy to tactic, and from discipline to discipline, the generalist can gain from taking the problems and solutions to pieces and examining what can happen in a

variety of instances" (Collier, 2006, p. 42). An eclectic approach of generalist social work practice is an important element of northern psychosocial oncology.

Collier (2006) argues that generalist social work practice is the best option when working in the north. Barter (2002) discusses "generalist practice being the desired form of practice in northern remote and rural communities" (p. 149). Johnston and Yanca (2007) define generalist social work practice as

> Practice in which the client and worker together assess the need in all of its complexity and develop a plan for responding to that need. A strategy is chosen from a repertoire of responses appropriate for work with individuals, families, groups, agencies, and communities. The unit of attention is chosen by considering the system needing to be changed. The plan is carried out and evaluated. (p. 458).

Schmidt and Klien (2004) identified strengths of social workers who live and practice within a northern community. The prominent theme was that the social workers believed practicing as a generalist was a strength of practice and it fit within the geographic northern setting. From this viewpoint then, my specialty position may need to find the balance between the implementation of generalist social work practice, the viewpoint of northern social work practice and the specialty knowledge of oncology social work.

"The stereotypical but often accurate image of the northern social worker is someone who is more of a tradesperson, relying mainly on interpersonal ability, ingenuity, and flexibility" (Tranter, Brownlee & Delaney, 2002, p.139). This image implies that northern social workers are not necessarily particularly skilled or knowledgeable. Yet, the ability to be flexible and ingenious are skills and it should not be viewed that social workers in the north

are less than their counterparts in the south. "Northern communities don't have the range and depth of specialized resources available in large urban centers, but this is not necessarily a bad thing as the social worker learns to develop the necessary supports and address gaps in service with local resources" (Schmidt, 2009, p.15). Schmidt and Klien (2004) argue that "northern generalists are also specialists. Generalist northern social work practice requires specialized skills and knowledge" (p.241).

Telehealth

Telecommunication is a type of service delivery method for social workers that can include telephone, computer, and video based communication. Telephone is the oldest and most widely known use of telecommunications technology for social workers (McCarty & Clancy, 2002). Telecommunication technology's early history included the use of the telephone and later progressed to video-based service. Video-based technology is used for interactive audio-visual communications between patient and providers, patient and family (support network) or provider and provider that allows timely access to specialist knowledge or enhancement of the plan of care. Videoconference is often used as a synonym for video-based technology (Institute of Health Economics, 2007). Tele-oncology uses communication technology for provision of oncology (cancer care) services to eliminate or reduce geographic barriers for cancer patients and their families (IHE, 2007). Telehealth refers to the use of information and communication technology to deliver health care services, enterprise and information over long distances (IHE, 2007). For the purpose of my research, Telehealth is used; however, the words more relevant lie somewhat between tele-oncology and video based technology.

Telehealth delivery for cancer patients needing psychosocial intervention is a delivery approach of social work practice that has existed since at least the 1980's (Broadstock & Borland, 1998). The basic premise of Telehealth service is that patients who wish to speak to a professional can do so – regardless of whether this service is provided face to face. Telehealth is a way in which the use of electronic communication technology can reduce or eliminate barriers to receiving psychosocial service (Vis, Turner, Brownlee & Shalay, 2009).

The Institute of Health Economics (2007) completed a comprehensive literature review to determine the use and benefits of tele-oncology. The literature review examined the type of tele-oncology services developed to assist patients and families throughout the cancer care continuum and the benefits of tele-oncology as a service delivery method. It examined 147 studies of tele-oncology: 45 of the studies focused on web based communication (internet), 40 studies looked at telephone services, 39 of the studies used interactive video based communication, and 23 of the studies did not specify a modality. It is important to note that from 147 studies of tele-oncology, no study used the term social work and only nine studies used either the term psychosocial care or psychotherapy. However, of the 147 studies, 32 studies used psychosocial related terms such as coping, support groups, counselling or emotional well-being. Of these 32 studies, only one used video based interactive communication (i.e. Telehealth). Further, only four studies referred specifically to rural or remote population bases; no study referred to north. The lack of studies with regards to Telehealth, social work and north may be reflective of the complexity of providing northern social work services via Telehealth.

Two issues with regards to psychosocial care and technology use are 1) that users must be comfortable with the technology and 2) that the therapeutic relationship may be

hindered (Doll, Stephen, & Poon, 2004). Doll et al. (2004) revealed that "several key informants indicated that discomfort with innovative communicative technologies on the part of health care providers as well as patients present a barrier to the use of technology" (p. 26). Additionally, technology may hinder the inherent interpersonal relationship between cancer patient and social worker due to greater difficulty in accessing non-verbal cues, establishing emotional connections, and dehumanizing patients due to lack of physical contact (Doll, et al.,2004). Cancer patients, however, may not view these issues as concerns.

Cancer patients indicate a willingness to engage with psychosocial support service via technology (Bauer, 2001; Eng et al., 1998; Gotay & Bottomley, 1998;). Kaplan (1997) compared therapeutic relationships in face to face or through face to face via video-conference and reported that an effective and therapeutic relationship is formed in both cases. McCarty and Clancy (2002) examined how relationship and effectiveness between social work counseling interactions is negatively impacted by Telehealth communication; none were discovered. Vis et al. (2009) state "technology is a more efficient and effective way than person–to-person therapy to service mental health needs of people living in rural areas" (p.95). Bauer (2001) discovered that therapeutic relationships are established through the use of technology and cancer patients report to having benefited from them. Studies demonstrate that cancer patients who receive psychosocial intervention through telephone or Telehealth have better emotional symptom management, have more confidence in the treatment in which they are receiving and have overall perception of improved quality of life. (Alter, et al., 1996; Cluver, et al., 2005; Kroenke, et al., 2010; Ohinmaa, et al., 2001). Not only are cancer patients willing to engage with psychosocial support (social work) via technology but also cancer patients benefit from the interaction.

A pilot study completed by Shepherd et al. (2006) focuses on delivering psychosocial care to rural cancer patients in Australia through video conferencing. The study's hypothesis is that psychological care through brief cognitive intervention to rural cancer patients via Telehealth will not only improve anxiety, depression, and quality of life but will also be an acceptable form of delivery. As well, the study aims "to determine whether video conferencing for cancer patients is an acceptable, satisfying and practical mode of delivery" (Shepherd et al., 2006, p.545). Cancer patients in rural and remote Australia who were identified as being distressed saw a clinical psychologist between one and six sessions via Telehealth. The results of this study are that patients QOL improved, anxiety and depression decreased, and that the majority of the patients were highly satisfied with the service. Shepherd et al. (2006) highlight that in communities with geographic isolation, conditions similar to northern BC, cancer patients often do not have access to specialized care dealing with psychological issues as well many cancer patient would not fill comfortable talking to a local professional in their community due to lack of anonymity. Both of these are likely to be conditions and opinions similar to cancer patients in northern BC. While Shepherd, et al. (2006) demonstrate that cancer patients in rural communities find benefit from clinical psychology intervention via Telehealth, the study did not examine whether the cancer patients would have received benefit through social work interaction via Telehealth.

In a similar study, Burns et al. (2012) attempt to determine what cancer patients and professionals experience when providing Telehealth. Patients had access to specialized oncology multidisciplinary care through Telehealth, and the patient and clinician rated the Telehealth sessions as highly satisfactory. Burns et al. (2012) point out financial benefits. "There appeared to be a financial savings for the patient, because by receiving specialist

intervention at a local facility, they avoided the travel expense above those subsidized by the health service" (p. 446). This study points to the benefit of Telehealth yet does not specifically examine social work intervention.

One potential drawback to using Telehealth service is that "most social workers tend to be attracted to social work precisely because of its personal rather than technological orientation. This is probably nowhere more true than in northern agencies which are very people orientated and community minded." (Tranter, Brownlee, & Delaney, 2002, p. 140). I agree with this statement because I needed to learn to be comfortable with the new technology in place. Through much trial and error, I grew to be comfortable in providing service in a different mode of delivery. However, throughout the years, the lack of face to face contact and engaging in and maintaining rapport with communities via technology was challenging at times. In the five years of providing this service to northern communities, I also had to consistently remind myself that I should not replace service which is already available within northern communities, despite fluctuations in each community's service level. "The challenge to northern agencies is to maintain the community focus that already exists within the north while using information technology to enhance the lives of those that live within it" (Tranter, Brownlee, & Delaney, 2002, p.146).

I am a Northern Health oncology social worker who uses Telehealth to engage with people and their families who experience cancer. I have worked in this role for over five years and with hundreds of people. The literature tends to support the value of Telehealth and the value of psychosocial oncology; yet, there is a gap in research with regards to Telehealth with social work. My professional experience has led me to believe that despite the gap in research, oncology Telehealth social work is beneficial to northern communities and has

value for patients: "The greatest value of technology was that it could gain patients access to programs that might not otherwise be available (e.g., for patients living in remote communities)" (Doll, et al., 2004, p.18). Through my work experience and from the literature, I have come to believe that it is valid to consider using Telehealth to help decrease distress and increase access of specialized care to people with cancer living in northern BC.

Chapter Three: Research Methodology

Research Design

The research design focused on gathering rich data about how Telehealth is provided to cancer patients who require or wish to have psychosocial service (essentially social work) within northern BC. It was hoped that the data would help bring meaning to my practical experience of providing this service to hundreds of people. It is through the use of phenomenological qualitative research that the following two questions are explored: 1) *What was northern BC cancer patients' experience using Telehealth service from a social worker? 2) What do social workers need to know in order to provide social work service to cancer patients via Telehealth?* The information obtained in this research study may be used to guide my, or others, future social work service to cancer patients in northern BC via Telehealth and to inform us on providing this service through evidence based practice. The following will describe the qualitative phenomenology approach, specific to this research. Then an explanation of the type of sampling, data collection and finally data analysis will be outlined.

Phenomenological Qualitative Approach

The virtual cup of coffee: Northern cancer patients' experience with social work and Telehealth is best suited for qualitative research study using phenomenology. This study examines several individuals experience with a common phenomenon. They all have cancer; they all used social worker services within the period of January 2010 to December 2011; they all used this service through Telehealth; and they all live in northern BC. Furthermore, I provided this service to all the participants. Thus the participants' and my experience are

representative of the phenomenon. Our experiences will perhaps provide insight into recipients receiving oncology social work and also guidance for future practitioners. A qualitative approach was used because "rich descriptions of phenomenon can be produced" (Marlow, 2005, p. 32). I focused the research primarily from the viewpoint that the participants' experience is based upon the assumption that they have a reality that is constructed based upon the societal context, an element of phenomenological qualitative research (Lopez & Willis, 2004), and that this reality is living within a northern rural setting. According to Creswell (2007)

> The best problem suited for phenomenological research is one in which it is important to understand several individuals' common experiences of a phenomenon. It would be important to understand these experiences in order to develop practices or policies, or to develop a deeper understanding about the features of the phenomenon (p. 60).

A qualitative approach is best suited for research when there is not a great deal of knowledge about the topic being researched (Marlow, 2005). It is important to understand cancer patients' experience of social work service through Telehealth in or to help direct future social work intervention using this method; further understanding of this through integrating a practitioners experience, my own, enriches the data and knowledge gained. Although my own experience is rich and meaningful, little data is available about social work intervention for cancer patients using Telehealth for Northern residents in BC. Thus the phenomenological approach fits for this study.

Another critical aspect about qualitative research, and more specifically the phenomenological approach to qualitative research, is that the researcher explicitly acknowledges the researcher's biases and values (Lopez & Willis, 2004; Marlow, 2005). I wanted to be cognizant that as the practitioner who worked with the participants, I had my own experience in providing the service. This experience led to certain interpretations on how I anticipated participants within their societal reality would respond to the questions. I did not want the phenomenon of my experience to unduly influence respondents' answers and my interpretations of those answers. Throughout the study, I openly acknowledged my biases and brought in social work values – mostly through the lens of northern social work practice. My literature review highlights generalist social work practice, and northern practice in connection with oncology. During the data collection with participants, I acknowledged this bias and encouraged participants to comment on it. For example, with one participant, I stated

> This is the last question, and it's a pretty general question. But it comes from my bias and my bias is that I live in the north, and I work with people from the north, and I think that it's important to be able to provide services from a north kind of perspective. And I want to be able to give whatever information the participants I have to other people that might be interested in doing this kind of services in the future. Now, because of that, I'm just wondering if you have any comments about that, or anything that you believe might be important to pass along around doing social work and Telehealth in the north.

Although this is one statement to a participant, with the others, similar statements were made.

Within the phenomenological approach, open disclosure of bias is critical in order to help to avoid undue influence upon the participants being researched (Creswell, 2007). This open disclosure also helps to insure that the reported meaning and understanding of the participants' experience is truly reflective of it and not an overly biased interpretation based on the researchers pre-understanding.

While freely admitting one's bias is important, a researcher must go further in order to ensure that bias does not affect the study and that the study is considered meaningful in its enquiry. A further step which I took to shelter my biases from the data was that I was interviewed in a semi-structured interview process using the same open ended questions that participants were going to be asked. I gave my assumptions as the answers to the questions. My interview occurred three months prior to the actual interview of the participants. The interview was recorded and transcribed by another. I believed this was critical because I did not want the data analysis to only reflect my experience and my bias. I wanted the data to be available to two types of interpretations of the phenomenon: 1) what the cancer participants' experience was in their societal context and 2) what future social workers need to know about how practice can be influenced while providing this service while living within this phenomenon. Recording my interview was a critical step as it allowed me to look back upon my specific answers to the questions during the data analysis, and then to examine whether or not my questions posed in the interview process could be leading unduly towards my biases. If discovered, I was prepared to go back and re-interview the participant acknowledging the misleading interview question, and exploring the answer with the participant again. Interestingly, in the data analysis process I discovered that I used very similar language in my answers as many participants such as "comfortable", "personable", and "friendly". Once

recognizing this, I looked at my questions to see if I used these words in the questions posed to the participants. I did find that I used the word comfortable in one question to participants Sara and Shawna. Fortunately, after close examination I realized that I used the word comfortable in a question after Shawna had used this word in a previous answer. I concluded that using the word comfortable did not come from my biases but was a reflection of previous statements made from the participants. I felt that engaging in this step was important as I did not want my biases to guide my interview processes or interpretations of the data, as the emphasis of this study was not on my presumptions but on participants' experience. I wanted to discover new meaning and explanations about the phenomenon under study.

Sampling

The participants were obtained through a blend of purposive and purposeful sampling. "Purposive sampling allows the researcher to handpick the sample according to the nature of the research problem and the phenomenon under study" (Marlow, 2005, p.138). The type of purposive sampling was criterion and availability. First, participants were residents of northern BC with cancer or had been treated for cancer and they had used social work services through Telehealth within the time frame of January 2010 to December 2011– which meets the definition of criterion sampling (Marlow, 2005). Secondly, the participants were available and able to participate in the interview, meeting the definition of availability sampling (Marlow, 2005). Recruitment of the sample was obtained through a poster describing the study within the cancer clinics in northern BC. There were seven participants recruited. Unfortunately, I believe not all potentially eligible cancer patients were available for interviews due to the nature of their cancer disease. A purposeful sampling method was

also used in recruiting participants. "In purposeful sampling, the most important guiding principle is maximum variation; that is researchers should seek to include people who represent the widest variety of perspective possible within the range specified by their purposes" (Higginbottom, 2004, p.17). At first, I believed that maximum variation would require turning away potential participants who would request to be in the study. However, this was not the case. All participants came from various northern BC communities. Their cancer stages and diagnosis were different. Their reasons for social work intervention or service vary. The number of sessions with a social worker fluctuated amongst participants. Finally, participants had varying partner statuses; some participants were interviewed with their partners, others without and some did not have a significant life partner. Perhaps due to the way in which cancer can impact anyone in society or due to large geographical area in which I have provided service or due to the personality or disease stage of people who first saw and requested to be in the study, I was able to find variation within the first seven people who responded to the poster advertisement.

There is often debate about how many participants in a sample are needed for data collection in qualitative research. Some argue that a particular number of participants is not necessary per se; but the meaning or interpretations which result from the data obtained is what matters (Sandelowski, 1995). Others argue that in qualitative research, data saturation is what needs to occur in order to provide meaning to data (Mason, 2010). Data saturation is when no new or emerging information is obtained or needed in order to make theories or elicit new knowledge of a phenomenon (Saumure & Given, 2008). Guest, Bunce and Johnson (2006) argue that it is possible to achieve saturation of data with a sample number of six for a phenomenology qualitative research; Creswell (2007) recommends between 5-25.

In this research study, the data collected was through a sample size of seven participants. For the purposes of anonymity the names of the participants were changed to the following: Chris (cancer patient) and his partner Jenny; Sara (patient) and her partner Shawna; Pam; Bob; and, Sandra. Although seven participants may appear to be a somewhat small sample number, I found that the data obtained from the participants was rich and meaningful and that common themes seemed to emerge from the responses.

Data Collection

In order to collect the data, I conducted interviews with the seven participants that were semi- structured with a list of open ended questions. (Appendix C) This allowed me "more freedom to pursue hunches and improvise with questions" (Marlow, 2005, p.167). The open ended questions were chosen in a way to help focus the research on gathering the textural description and structural description, which meet criteria of qualitative research (Creswell, 2007). Although in principle, I had the ability to pursue more questions in the interviews, I did not stray much due to being a novice researcher. As well, given my practice knowledge of all the participants, and a clear message from the NHA Ethics Committee, I was very careful not to pursue questions that may lead to some coaching or information or to identification of the participants. In the interviews, I also clearly outlined at the beginning of the interviews that firstly in no way would the information that they shared impact their health care treatment and that secondly if they felt uncomfortable with being interviewed by myself or if they preferred someone else to conduct the interview, this could be arranged. None of the participants articulated that they wished to pursue this option; participants appeared to freely discuss and answer the questions. The interviews fluctuated in length with the shortest interview lasting 31 minutes and the longest interview was 1 hour and 12

minutes. The majority of the interviews were approximately 45 minutes. The interviews were tape recorded and transcribed for data collection.

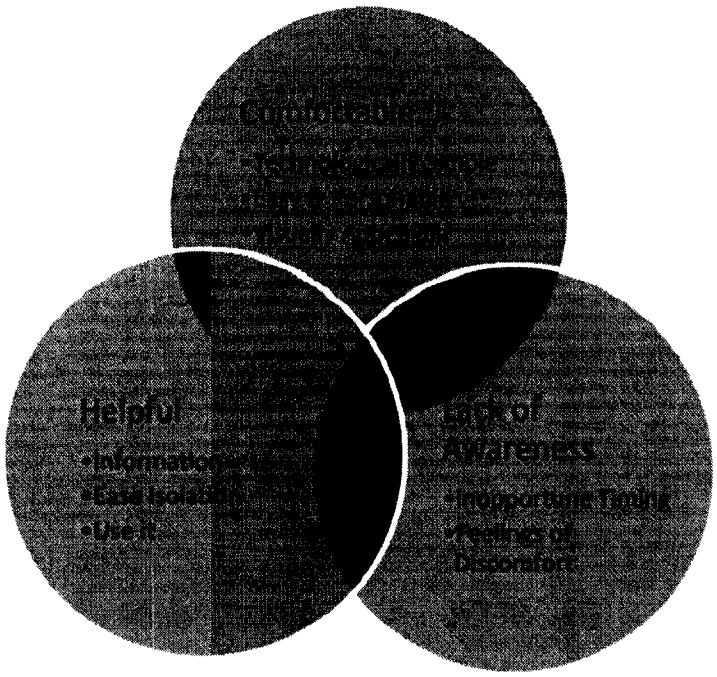
Data Analysis

The data was analyzed through techniques outlined by Creswell (2007) when using a phenomenological approach to research. The first step was to fully describe the researcher's own experience with the phenomenon under study. This was achieved through myself being interviewed (as previously mentioned) three months before the interviews were conducted. In my interview, I described what I thought the participants would state. I shared common viewpoints with the participants yet some of the themes that emerged or did not from the interviewees were not expected. (This will be expanded on within the discussion section). The next step in data analysis was to develop a list of significant statements from the interviews with participants. Although this step appears simple in nature, for myself, I struggled. The focus was to have a comprehensive non-repetitive list. Often this technique is referred to as horizonalization of the data. Unfortunately, many participants had similar significant statements, which led me to grouping and categorizing the data into themes early within the process. I was eager to form interpretations from the data, making the data meaningful for myself. I believe this was in part due to my professional attachment to the answers found within the data; I was working with this research population base and wanted to improve upon my practice. I often jumped into the discussion portion of the analysis without truly completing it. After many struggles of finding the analysis lacking, I re-grouped and recognized that I needed to start over. I printed up all the interviews, and literally, I went through the interviews word for word and statement by statement cutting out with scissors anything that appeared to be significant. I had over 200 significant statements. From this

significant statement list, I then had the potentially difficult task of categorizing statements into themes. Luckily, an unfortunate accident occurred which provided a means of transforming this task from being difficult to falling into place. Due to a year leave from the analysis because of a car accident, I was able to look at the significant statement list with a fresh perspective. I believe this fresh perspective allowed me to accomplish a thorough analysis of the data, and not a premature closure of data interpretation. I then wrote a comprehensive description of what the participants experienced, normally referred to as textural description. In addition to this, I made a diagram in order to visually grasp the textural description making the "what" more easy to identify. Following this, another comprehensive description was written detailing the structural context essentially the "why" within the phenomenon. Again a diagram helped me to see it. After this, I reviewed my initial interview of myself and incorporated my comments into both descriptions. The last step was to incorporate both the textural description and the structural description into a thorough interpretation providing the essence of the experience (Creswell, 2007). An important element of the essence is the blend of the participants' phenomenon of social work service through Telehealth and my experience of a practitioner providing it. This excerpt is ultimately outlined later in the discussion section of this paper. My work experience and literature review were used to layer the textural (what) and the structural (why) phenomenon to stimulate understanding for future social work practitioners providing this service.

Chapter Four: Results

Summary of Textural Description



The data results for the textural description are broken into three themes: being unaware of the service; being comfortable with the process; and finding the service helpful. A general lack of awareness resulted in two sub-themes: feelings of discomfort and inopportune timing. The theme of being comfortable with the process had three sub-themes: easy and personable, visually appealing, and technologically simple. The last main textural theme was finding the service helpful; and it produced three sub-themes: information, ease isolation, and use it. Each of these textural themes and sub themes describes the what of the experience essentially what happened in the service.

Lack of Awareness

When asked if the participants knew of the service before using it, the answers were universally similar: no they did not; or, they had heard of it, but did not know what it actually was. Pam's response to the question of if she was aware of the service was: "No I wasn't. I was, when I went up to the oncology here in town here, the nurses there, they informed me of, they sort of explained it to me before the teleconference started".

Sara responded to the question of her prior knowledge of this service as "actually not a clue."

Sandra explained

> I really didn't know what it would be like. Would they be helping us? Would they tell us what to do, or did they just say you know whatever, were they there to help us? Like I honestly didn't know what it was all about.

Bob stated

> I really wasn't aware of what or what it would be or I didn't really have a clue of what was going to happen or it was pretty it was pretty all new to me actually.

Due to the general lack of awareness of cancer care social work service through Telehealth, participants felt discomfort and believed that the timing of the service was inopportune.

Feelings of Discomfort

The lack of awareness of cancer care social work service via Telehealth led to being nervous, apprehensive or uneasy about the service and interaction - generally feelings of discomfort. These feelings were based upon not understanding the role of social work with cancer patients or the way Telehealth works. Pam stated that "I didn't know what to expect or

what to, you know, to do or whatever". Sara stated "it was really, really good for me, and I was I was nervous going into it". Chris' partner, Jenny, explained

> due to some horrible, horrible incidences with social work at Children's Hospital and more recently with our daughter having had back surgeries down in the spinal cord unit in Vancouver and her dealings with the social workers down there we had really hoped that we would not have to deal with social workers in the predicament that we're in.

Sandra explained

> It was very helpful once I got over being nervous wondering what was going to happen. Speaking to you everything was fine, it's just I didn't know what to expect or what to you know to do or whatever, but once like once I knew what was going on then it was fine. I felt more at ease and could get help.

The feeling of discomfort was not an unexpected theme to emerge as I believed that participants would imply this. I had been told by patients and health care providers that people are apprehensive to use Telehealth and felt uncomfortable and that many people with cancer in northern BC do not recognize the value of social work for their situation. So, the combination of meeting with a social worker through Telehealth would perhaps provoke feelings of unease. In my response of the interview of what I believed participants would say, I stated

> I've had feedback that it wasn't as painful as they thought it was going to be. I think that they'll say that perhaps the first few minutes they were a little bit uncomfortable, but then they actually just forgot that it was there.

Inopportune Timing

Because participants were unaware that this type of service was available to them or how it would benefit them, they did not always engage with it at the right moment. Once they were made aware and then agreed to use it, participants felt that they would have benefited if they used the service earlier. Pam described that before using the social work service, she had already been given information to help her. She also disclosed that she had previously known about the social worker service but elected not to engage with it until her health care provider recommended it. Pam stated that interaction with the social worker as:

> asking you about financial stuff and all that, but then that was sort of, I had that all arranged through like where I worked ...it was like making sure that I had all the information and if I knew about how to access you know certain things that I'd already been informed through my boss here in town.

Jenny stated in reference to information and resources as "a lot of these things were not pointed out to us until either right at the time, or after the fact." Chris described his experience in trying to find information, and that the social worker was not particularly efficient in getting it to them at the opportune moments. He suggested that the social worker improve in getting information to patients.

> I know it seems like you know there might be a lot of homework initially to set up a database but to me once it's in there it could even be advertise a small website like go here, and here is everything that you need to know about every possible avenue of help. Financial, buses, accommodations, and everything, but right now you have your little area and you know sort of what you know. In whatever form I guess that you or the social workers would be able to and during a Telehealth conference as you're

getting to know the people cuz now we're getting personable, right? And then you know as appropriately as it comes up and then be able to say well this is you know here's the information place to go. Here's the website number or you know we can email you uh you know the information you need, and I think and I would, from a stress point of view I think that would that would help.

Comfortable

Participants described their experiences as being comfortable which is the second main textural theme. Pam stated "I felt quite comfortable. I was just sort of listening to them and uh asked a few questions." Sara's partner, Shawna, explained that it "was pretty good experience because it worked really well. Very comfortable." Sandra spoke of her comfortable experience as

> the person that I was speaking to was very calming you know and explained things to me and asked different questions that was you know was great, but yes it was very easy to speak to the person. Made me feel at ease.

Easy and Personable

The participants remarked that the experience was easy and personable; both are subtheme attributes of the comfortable experience. Sara described the experience as "it was very easy". Shawna explained further "it worked so well that when you actually came to see us in the hospital in person it was like we knew you." Pam recommended that the service continue to be easy in the future:

> One of the things is make sure it's set up for the patient so that it's easy for them...and all we have to do on this end is turn it on. I'm not very good at all this technology business, but this way it worked.

Bob highlighted his easy and personable experience through his recommendations to future social workers providing this service.

> For my perspective to make it personable like don't just go in and okay you know this is it, you gotta keep a stiff upper lip, I was I was made to feel like real comfortable, it's you know make the, get the person comfortable because it's a big shock, and make it easier feeling you know they're there for them and it almost make it easier for them to open up if they're comfortable more dialogue going. Sometimes it even takes maybe it might take five or ten minutes because if you don't, if you're not getting the feelings out what the person's really going through. It may not be as effective. Whereas if you take your time and sometimes you can be talking about the weather that it just takes that to get, this person to feel comfortable with this person. So it's that kind of thing like take the time to get to know the person that's on the other end.

Jenny describes the experience in the following way

> Like you put us at ease right away. You personalized it by calling us by our first names, which I truly appreciated, you acknowledged that we were wearing coats so you asked about the weather. You just gently eased us into what we had thought was going to be a very difficult, non-beneficial situation. You walked us through it all and I know for myself I felt very comfortable and with the giggles that we shared and you know, close to a few tears a few times you were able to walk us through the whole

process. We left our first meeting thinking "Boy, we have an awesome contact." We felt a huge relief. We honestly felt that we had been helped.

Visually Appealing Experience

A sub-theme of a comfortable experience was based on the ability to visually see the social worker. Bob described

> It was just like it was a human being there. It was something that like I've talked on the phone before but you know with people in in different parts of the world for work and you sometimes you just get the opinion, think that they're just sort of saying yeah, yeah, yeah, and off the phone and to the next person or whatever. Whereas here, seeing that face, seeing the body movement, the expressions, the smiles, they just made you feel so much more comfortable.

Chris informed that

> Initially like we were thinking oh jeez this, I don't know if I'm gonna like this being kind of a not much of a telephone person, and I wasn't really sure what to expect, but after having you know it only took a few minutes into the initial one that we had and it seemed to work out well and you know I think putting a face to a name and that really helps and I think barring having a one-on-one personal meeting I think it it's the next best thing, for me anyway.

Finally, both Sara and Shawna spoke of the ability to see the social worker aided in their general overall satisfaction and comfort with the experience. These comments are closely tied together with the other sub-category of technologically simple.

Technologically Simple

A sub-category of comfortable related to the simple way the technological was blended into the experience. Sara and Shawna commented on the technologically simple experience. Sara states, "It was it was it was very odd at first because we're not really up on technology. I mean we know it exists but we had never ever seen it working in action and be involved." Shawna elaborated about how the Telehealth experience, the technology worked with the service.

> It be like little details like the bell curve that you drew. Yeah. And you can you can, we could see it very easily and you know you hold up the paper and then it's magnified on the screen, so that worked very well.

Dave explained

> the cancer care team you know ensured that the room was set up and you know everything was done on time and you know the door was closed for privacy and stuff. So I mean they also did their job I think their bit to encourage the process too.

Pam explained "all we have to do on this end is turn it on. I'm not very good at all this technology business, but it was simple"

Helpful

Participants described social work services as being helpful. Chris's partner Jenny stated " you have certainly been very very helpful with us you know any way that we can give a little back that's what we would like to do." Sandra stated "it was very helpful once I got over being nervous wondering what was going to happen." Sub – themes existed in the

way in which it was helpful. These are information relevant to cancer patient's experience, easing isolation of the cancer experience, and recommendations to use it.

Information

Jenny spoke of the help they received in social work experience through the information provided: "even if you don't have the answer you seem to know who to point us to and the follow up that has been provided up here to ensure that we have received those answers has just been amazing." Despite Jenny speaking positively about the information that they received, Jenny also stated

> Now I know that our experience has been nobody has ever told me one place to go for information like even just as simple as you know if you're having a hard time with money you know that you can get a hold of BC Medical and have your premiums waived. You know what I mean? Like looking at one-stop shopping for potentially all the avenues of help.

Pam described her thoughts prior to and after contact with the cancer care social worker. "And I just thought well it would be good to go through it and probably be very informative, which it was you know". Sandra stated

> I think it was really helpful because you, we could you know, make, give ideas to you and the other way that you know we wouldn't maybe have otherwise anywhere else. Maybe not so much for myself because I have, you know my husband is a solid supporter, but and questions I have and you know so I think that a social worker, the way you are doing it, was just fantastic.

Sara's partner, Shawna highlighted that the social worker provided information for them relevant to the cancer experience and eased their distress and isolation.

> Actually you know I thought this is something you have to go through all by yourself and then if you think of something you can always phone one up and ask. I don't know. But I never thought it would be such an important part of the process as it is. There's so much we didn't know.

Ease Isolation

Shawna's statement above also speaks of how the cancer experience with a social worker eased their isolation. Bob spoke of the cancer social worker experience as helping to ease his isolation of the cancer experience.

> You know what, the biggest I think doing it that way was I know I'm not alone. There's help there.... It's like you know aside from the doctors, aside from the nurses, there's somebody there that's you know what, you can ask a tough question or you can ask like how just, they're there with you. It's just that they're there to help you. They're, it's just so more personable I guess, more comfortable. And you know to get, like I didn't I didn't even, you know except for the people at work, I didn't tell anybody except for my immediate coworkers, not even the guys on my crew and stuff like that. And after I talked with the social worker it was, I just, you just, I felt so much more at ease that, you know what, like I'm not the only one out there, there's you know, there's help there and it made me more comfortable even to discuss it with other people.

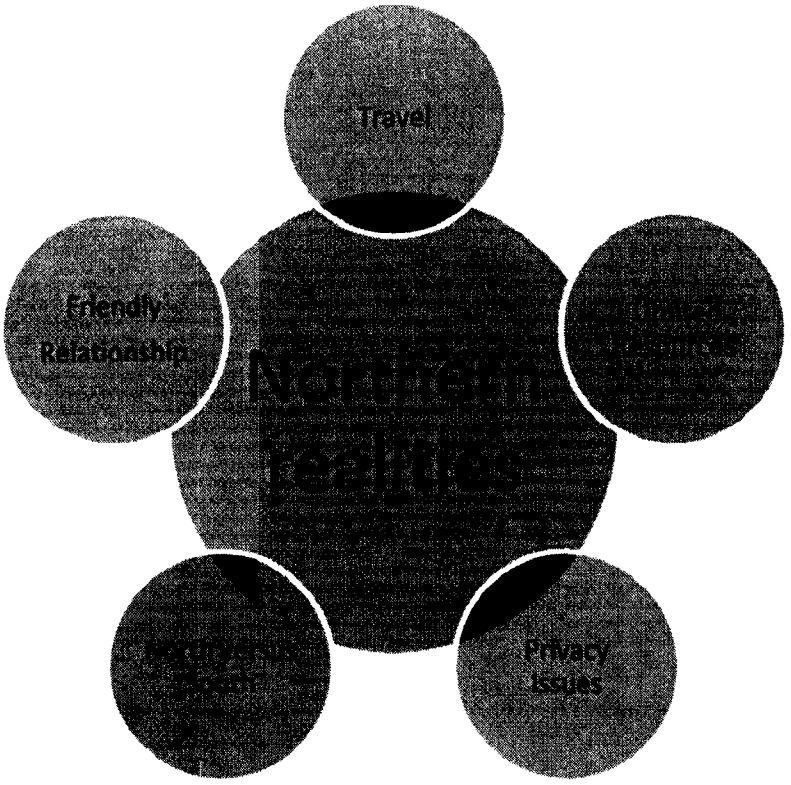
Use It

All the participants stated that they would refer others to use the service. The participants stated this in varying ways. Although Pam had spoken about the fact she had been helped before her interaction with the oncology social worker, she stated that she would tell future patients that "it pays to, it pays to talk to them (social worker) about it (cancer experience)." Jenny said "Try it. Until you have experienced it don't have any preconceived notions about entering into it. Try it." Her partner Chris expanded onto Jenny's comment:

> Yeah I agree. Like I said you know I was going into it thinking that I really don't you know not being a telephone person I didn't know what to expect so I think to go into it with an open mind.

Shawna stated that she would tell other people experiencing cancer that "It was important to us to be able to connect with a social worker and I didn't think it would be." In response to the question of what Bob would tell other cancer patients about social work and Telehealth, he stated "I'd just say it's a fantastic thing and use it." Sandra's response to the same question as Bob's was simply "Go for it". Interestingly, these answers were what I predicted the participants would state, and in fact many of the participants used the same words as me. "Go for it. Do it. Give it a try because you have nothing to lose. There's probably not a service in your home community."

Summary of Structural Description: Northern Realities



The structural description of the data can be simply summed up in one theme: northern realities. The structural description is different than the textural description. As mentioned earlier, the textural description was the "what" of the experience; however, the structural description goes deeper and draws out the meanings of the what. It is the "why" of the experience. The theme of northern reality was displayed through five why subthemes: north versus south, limited resources, privacy challenges, travel, and, friendly relationships.

North versus South

Chris's partner Jenny described the north versus south context in the following way:

You treated us as a friend. Somebody that needed your help and you went above and beyond to provide that. The social workers that we dealt with in the Lower Mainland

> we and our daughter were treated as a number. We felt like a total inconvenience to them. And other than providing us with minimal information, they would not or could not think outside of the box and they just basically blurted out a bunch of facts that I think they read from a book of regulations and they would not discuss anything beyond that point. Our daughter tried to make arrangements to get home from Vancouver after being air - ambulanced down there. The social worker advised her "you've been given your prescriptions. You need to fill them." Our daughter was in a wheelchair. She had to wheel herself out of the hospital, I'm not sure how far to the drugstore to try and get these prescriptions filled. She was on a very short time frame for having to catch her flight. She handed in her prescriptions. She waited for almost an hour before the pharmacist got back to her and said "your surgeon used the incorrect prescription pad. We cannot fill this." She had to make her own way, in the wheelchair, back to the hospital to get the prescriptions corrected and then wheel herself back to the drugstore and then back to the hospital. She again contacted the social worker. By this point she was in tears, in a great deal of pain. She asked for some assistance to get to the airport and the social worker said "All I can do is give you a voucher for the taxi" and basically turned her back on my daughter and walked away.

Sandra stated "it seems like we do not have as much help in the north as they do in the south area." Bob attempted to explain the importance of northern interactions through his interactions with support during his journey. He explained that the benefit of the northern cancer social worker: "but to me it's like the you know um you know work from the north and it's like you know you take care of our own." Chris stated

> what appears is that in Northern Health, say you and everybody included treat people like human beings up here like you know, the old hometown kind of people. Whereas down there you are just a number that as quick as we can get you in and out, get lost and I gotta move on to my next person or client or whatever the term that we're going to use today, right? So, if, I think in the Northern way if we look at keeping that style of work going which I think is, would be effective and it's good.

Chris also mentioned that once the research was complete

> I would love a copy of that and I would love to take it down to the Lower Mainland and strongly suggest to them that they do a practicum or be mentored up in the North before they start practicing down in the Lower Mainland.

Limited Resources

A subtheme of Northern realities is resources. As a structural description from the participants, resources as it relates to the lived experience appeared in subtle yet very important ways. In looking at the way lack of resources is highlighted, Pam highlighted the importance of the Telehealth availability:

> Well it would probably inconvenience a lot of people because you have to drive well an hour in, an hour and a half in, and then an hour and a half out depending how fast you drive. And then you are probably spending a couple hours in there.

Shawna mentioned something very similar and then suggested that the service be expanded as despite it being available, it was not easily accessible.

> Well it's a big deal because you know when we drove to the hospital when we got

> your service, that's an hour and a half drive, but some people are further away than that and so it's I think it's really important to expand it if it isn't all over.

Participant Bob explained that "the service is there and you know and I firmly believe in the you know you have to use it or you could lose these services, right?" Participant Bob's doubt in the sustainability of the service demonstrates the northern context of limited resources. Participant Bob further explained "I was happy to do it because you know you know any services that we can keep and get in the north is I think it's fantastic". Chris spoke of the lack of services in the following way:

> you know there are services that people really need, really need, and there are services that people that should and can, can and should be paying for by themselves, and I don't know if that falls into you know anybody's line of work, but it it's just one of those, resources are limited, right?

Travel

Travel and the amount of time it involved for people with cancer in the North was a subcategory of northern realities. Chris spoke of it this way:

> I guess my perspective I'd be looking at for social work services probably unique up North is that we don't you know we're not just driving you know fifteen minutes or an hour into you know the major centre we can get all our treatment. We spend a really large amount of time I think in the North, either flying or driving, and I think it's important for information-wise, to know what services are available.

Shawna described the impact of traveling to receive service.

> It's a big deal because you know when we drove to the hospital when we got your service, that's an hour and a half drive, but some people are further away than that and so it's I think it's really important to expand it if it isn't all over....I still think the best difference is that we that we have the service right there while we were in the hospital in that little office. We didn't have to go anywhere else.

Sara spoke of the travel in relation to the service as "we didn't have to drive who knows where to actually see someone." Pam mentions:

> If it wasn't through the teleconference, then I probably would have had to go to Prince George, right? And travel. I don't know if they have anyone around "community". I doubt it. Not through oncology, or else they wouldn't be having it on the teleconference thing.

Privacy Challenges

Sandra spoke of the benefit of Telehealth in that it facilitated privacy which is difficult to achieve within the North.

> There's lots of questions that you know, maybe wouldn't ask somebody else you know, like me and my husband we do, but I think there's other people that are struggling a lot and this I think would be helpful if they realize that once they're over their nervousness and it's all confidential, there's nothing they cannot ask, it's great.

Sara spoke of privacy in that that "we were in that little office by ourselves, so it we had privacy. And we didn't have to drive who knows where to actually see someone." Chris agreed to his wife's, Jenny's, statement that after the first interaction they felt that they had been helped. In reference to how he felt he was helped, he stated "the cancer care team you

know ensured that the room was set up and you know everything was done on time and you know the door was closed for privacy and stuff." Jenny stated "I think it helps a person uh 'cause you don't know this person so you can kind of talk freely, more open than if you do if you know somebody". I too also believed that participants would allude to privacy issues.

> I think some participants might actually say it was beneficial to them because they felt more comfortable talking to me um about counselling matters than somebody in their own community because the anonymity um is remaining there. So I think, that's what I think they're going to say

Friendly Relationships

A further subcategory to the northern realities is relationships. Relationship for the participants' was defined slightly differently, but all highlighted the relational interaction within their experience as friendly, informal professional contact. As Bob commented

> You know you come in and it was like, I think we even made the comment on the coffee cup, like it was just the whole thing. And, you know what, that may not mean anything, but to me it's just, it was like I wished I could have had a coffee with ya. Two friends having, you know two friends you know going to the coffee shop and talking and you know having that heart-to-heart talk. And to me that that's that that that just hit it off for me and right away I knew right "You know what, this is going to be okay. This experience is going to be okay." Because it connected on that level and in some instances it might not have been the coffee cup, maybe it was, it could have been the person does bouquets and there was a bouquet on the table or you know, but it's finding that that common bond with that person who's going to be

pretty pretty nervous to begin with and I think you were very good at it. It just it was good.

Shawna described the following situation according to Sara "she said that it worked so well that when you actually came to see us in the hospital in person it was like we knew you." Sara further added, "that personal touch is there whether you're in your office or on the screen". Jenny gave recommendations to future social workers providing Telehealth

> if you're going into it I think on a friendly note, as personal a note as you could and I guess still maintaining you know a fairly I guess a bit you know I don't want to say business-like but kind of on-track I suppose, if that makes sense

Further Jenny remarked "You treated us as a friend. Somebody that needed your help and you went above and beyond to provide that". Later she elaborates

> It was almost like you were just sitting across the table having a cup of coffee with us. You know having never experienced anything like that before, when we first went in I thought "Okay so what is this? Basically just like a televised show where this person is going to be sitting there telling us what we need to do, what we should be doing, how we should be feeling." But because you acknowledged you know what we were wearing, how we were seated, like I say, it was like you were sitting across the table from us and it made it very informative, but very informal, which we, or I, appreciated.

Chapter Five: Discussion

Introduction

The study was undertaken to provide some meaning to two questions: what is northern BC cancer patients' experience with social work and Telehealth, and what do social workers need to know in order to provide this service? Interestingly, as the data analysis is separated into the textural and structural, meaning is provided for the first question of the study. I believe further discussion is needed that specifically looks at how the textural and structural analysis can be interpreted in such a way as to address the second question. The textural component has been described as the "what". I view the "what" as the practical element of social work practice. It is the actions of the social worker and interactions with him or her and the client through Telehealth. This helps me to translate the data into practical information that social workers can use in the future. The structural analysis provides the "why" to the data. I believe this provides the theory to the practical elements. It helps social workers join the practical elements to the theory of practice. This theory is grounded in the political and societal context of northern social work.

Initially, the textural analysis appeared to produce a greater number of themes or insights into practice components of social work than the structural analysis or the theory of practice; however, this is misleading. Each theme within the textural analysis is represented in some way within the structural analysis. Not surprisingly these are northern realities. To sum it up, Issac and Stokes (2009) speak of being northern minded

> Socially and psychologically, people self – define their daily life experience as being northern, small community, or rural. It is this experience that differentiates the

inhabitants of these communities from the majority of Canadians living in larger, urban, often (but not necessarily) southern cities. (p. 171).

An excellent example of how important northern realities are is when participant Jenny spoke of her daughter's experience with social work in the lower mainland (p 60). Viewing Jenny's daughter experience without a northern lens, one may not see the hardship which the social worker exacerbated. One may see that it is unfortunate for this woman in a wheel chair to have to wait and be inconvenienced with traveling back and forth, to hospital and then drugstore, but these events are normal. However, when one views this from a northern lens, one can understand the urgency and distress that each task places on the woman. Firstly, when people are flown via air ambulance to the lower mainland, it usually is on an emergent basis and rarely do people arrive knowing that they will be discharged from the lower mainland and expected to return to home community on their own. Thus the patients are unprepared. The patients are discharged from hospital and need to find a pharmacy in a location and city that for many is foreign, busy, and perceived as the big dangerous city. While they venture into the city, they may further have the aspect of pain due to recent surgery and be impaired due to medications. If they are flying home, for some there may be only one flight a day leaving the south for home, and if they do not catch the flight, they are then required to find a hotel and spend yet another day away from family, friends and the comforts of home. Furthering this urgency to not miss the flight is the fear and burden of additional costs for missing a flight; depending on where in northern BC the patient is from these costs can be over $1000. When viewing the situation from the Northern lens, one could see easily why the interviewee expressed the social work experience as being horrible.

In order to help future practitioners, a discussion that highlights the way in which the textural analysis is embedded within northern realities needs to occur. This discussion will draw upon literature, northern social work principles of practice, psychosocial oncology, and my practical experience.

Eclectic Approach to Practice

As mentioned in the literature review, psychosocial oncology and generalist social work practice is eclectic in its approaches, and has a wide variety of subject matter or situations in which to deal with. One can see with the case examples the variety of issues that faced these people dealing with cancer. For Joe, he experienced housing issues and a serious deteriorating health; the social work interaction dealt with lack of resources and provided advocacy. For Alice, social work interaction focused on clinical counseling skills in order to assess grief and loss versus depression. Finally, for Al, an eclectic approach was needed using support and crisis intervention combined with knowledge of palliative care. The data gathered demonstrated that a large knowledge base as well as skill set is needed when working with the patients interviewed. Some discussed that practical solutions and information was important to them. Sara states "we were just kind of hoping that there was some little tidbit (of information) that would give us some help because we were pretty much in shock and desperate." This was a textural theme of information. Others spoke about the need to talk about anything related to cancer so as not to feel alone, reflective of textural theme of ease isolation. As Bob stated

> It's a big shock when you find out you have cancer and then right away it's you know it's almost like you're left in your own little corner of the world by yourself, and to know that that option was there was fantastic.

Jenny states in reference to dealing with social workers from the lower mainland,

> the next person you phone, they only know what they know, and they don't think outside the box to tell you even another person to phone. You spend a lot of time and anxiety trying to find these potential services.

This statement can fit into the textural theme of lack of awareness. It is also reflective of northern realities: north versus south, and limited resources. Further it shows that northern social workers need to think outside of the box due to lack of northern resources and geography. Another participant suggested a large data base of resources in order to help people in the north from the onset would be helpful instead of northern residents searching and looking for relevant information on their own is indicative of both the textural theme of inopportune timing or lack of awareness and the structural theme of lack of resources.

I believe that looking at the participants' statements on their own would be detrimental to any future social worker attempting to provide cancer care services in the north. This is because the data does more than just suggest being eclectic in approaches. It highlights the need to understand the reality of being northern minded and living in northern BC.

Complexity of Northern Realities

Complexity of northern realities is demonstrated through the data in terms of the what within the analysis. For example themes that arose in the textural data were that the service was helpful; yet, there was a lack of awareness that the service existed. I believe that the themes of helpfulness and lack of awareness were embedded in northern realities and reflected within the themes of limited resources and friendly relationships. The way in which

these themes join together has been very difficult for me to grasp and to articulate. Sellick and Delaney (1996) describe

> To insiders contextual patterns may be so transparently obvious and 'given' that they may be difficult to even identify or articulate to outsiders until they have been violated. However, for 'outsiders', contextual patterns may be so transparent and unspoken as to be mystifyingly invisible. (p42).

In my situation, I feel that I walk in between two worlds at times; as an insider because I identify myself as a northerner but also as an outsider because I do not live within many of the communities I serve.

As I mentioned earlier, I had an accident which provided me with the ability to re-examine the data and to process the literature review several months later, thus, arriving to the following conclusion.

As a social worker who has worked with northern BC health care for over ten years, I understand the importance of the relationships between patient and health care practitioner. Before interviewing the participants, I believed that patients used the service because of the relationship with the health care practitioner and the referral from this person. In the interview in which I provided my assumptions' to participants' responses, I stated

> I think the majority of them have learned through direct referral from the general practitioner of oncology GPO, or the nurses that are working with them in the chemo clinic. I think that's really the only way that they've learned.

Despite this expectation, I was still surprised that the participants did not seek this service or know of this service prior to the referral from the health care practitioner. As the promoter of

the resource, I know that I not only informed the different key stakeholders of the community of the service (oncology nurses, General Practitioners of Oncology, Allied Health Services, Canadian Cancer Society) but I also had posters placed in the community oncology clinics and pamphlets of my service given to every new patient. The literature states that cancer patients regardless of their stage in treatment or in prognosis experience distress (Andersen, 1992 & Zabora et al., 2001). The participants did not engage with the service even though they may have been experiencing distress; and, they did not have to travel long distances to receive help. If this is the case, then why not seek out services available within the health care community? Why did the participants not know this service existed? There are several possible answers. Patients when in distress may not be able to focus on or recognize information that is given to them. Patients may not realize the importance of seeking help for the psychosocial aspects of their cancer treatment. Patients may not have the energy to engage in any other aspects of treatment except the medical treatment. Patients may have heard that the provider of the service was not helpful due to northern concept of community microscope. Patients may dismiss the notion that a social worker has skills or values pertinent to their situation. Of all the possible answers, my experience with now over 500 patients speaks to the fact that northerners value, acknowledge, recognize and utilize service when it has been recommended; especially when that recommendation comes from their own health care provider. Kraetschmet et al. (2009) speak about how important health care professionals are in connecting patients with resources in rural settings; essentially they play a gatekeeping role.

> Health services researchers define 'gatekeeper' as a provider who is responsible for overseeing and coordinating all medical needs of a patient. The gatekeeper must

> authorize any referral of the patient to a specialist or hospital. We found that the requirement for a Telehealth activity to be scheduled at the provider site acted as a form of gatekeeping that controls, if not eliminates, the opportunity for individuals outside the predefined geographical area of a Telehealth program to access the service unless permission is granted. (Kraetschmer et al., 2009, p.661).

Regrettably cancer patients in the north may wish to receive social work support; but, because of their reliance on the expert health care practitioner for access, they may never receive the professional service. This leads back to interconnecting themes of helpful, comfortable, lack of awareness, limited resources and friendly relationships. I believe the link with them all is the inherent importance of relationships in the north. A social worker wishing to provide Telehealth service requires a working relationship, perhaps even a friendly relationship, with the 'gatekeepers' of the service.

Rapport Building

At first glance relationships are an important element in providing social work service in the north through Telehealth. However, if one digs deeper, it appears that what is equally if not more essential is the skill of rapport building. Rapport building is essential to any social work intervention (Derezotes, 2000; Johnson & Yanca, 2007; and Miley, 1995). With regard to Telehealth, its impact and the way it is achieved has perhaps greater implications on the service satisfaction than through traditional forms of interaction like face to face contact (McCarty & Clancy, 2002). Rapport building was imbedded in both the textural and structural components of the data. Participants spoke of the importance of friendly and

personable contact with the social worker through Telehealth. One way this was achieved through taking time to connect. For example Pam states

> the person that I was speaking to was very calming you know and explained things to me and asked different questions that was you know was great, but yes it was very easy to speak to the person. Made me feel at ease.

Behaving in a calm not rushed manner appeared to be an element that allowed Pam's experience to be comfortable. Addressing Chris and Jenny through the use of first names seemed to provide a friendly environment to the Telehealth interaction. Bob expressed his comfort and the importance of the relationship within in the interaction in the earlier mentioned statement of:

> two friends having, you know two friends going to the coffee shop and talking and you know having that heart-to-heart talk. And to me that just hit it off for me and right away I knew right away. You know what, this is going to be okay.

The importance of the rapport building and the relationship was not surprising to me as I anticipated the following in my statement

> I think that they would say that don't be quick in your interactions. Take the time to establish a relationship a little bit. Don't just come in there and say okay this is what I'm going to talk about and do a checklist. That's my bias. Just in working with it, but also in like literature around what is important for northern clients. Like they really hugely value relationships and meaning and that connection versus what type of information they get. So they actually perceive that they are getting better service if they've connected with a relationship even if you know clinically they might not have got as good a service.

Inherent within the rapport building is recognition of northern realities. Jenny spoke of the fact that during the social work interaction, I commented on their coats. She states

> Like you put us at ease right away. You personalized it by calling us by our first names, which I truly appreciated, you acknowledged that we were wearing coats so you asked about the weather.

Gifford et al., (2012) highlight the importance of a therapist understanding and acknowledging a client's culture and unique location as a core competency for delivering Telehealth services. My comment on the participants' coats is a reflection of my understanding that northern travel conditions, especially in the winter, are challenging and that it is likely that both Jenny and Chris just experienced difficult road conditions, given the time of year when they received service. As Schmidt (2009) comments

> While weather may exert some influence in an urban setting, the effect is minimal compared to the influence it exerts in northern social work practice. Many of us who work in the north experience the uncertainties of the roads that shift and change with the seasons (p.9).

A social worker with a southern or urban contextual viewpoint may miss this subtle yet so important reality to the patients he or she is working with, especially if this service is provided through Telehealth.

> Understanding contextual patterns in northern communities presents a complex challenge. While northern communities share common characteristics which may help social workers situate a community within historical/political/geographic contexts, efforts to understand a particular community solely in terms of those

> common characteristics will inevitably fail in conveying richness, diversity, and uniqueness of that community. (Sellick & Dellaney, 1996, p.41).

There is a real complexity of rapport building in order to engage in and maintain workable relationships in a northern setting. Rapport building is used to establish and maintain relationships. It is a critical component to the perceived usefulness of social work service in a northern setting and even moreso through the use of Telehealth.

Isolation

Interestingly, I myself did not anticipate that participants would highlight that the service eased isolation; however, this is not an unexpected theme to arise for cancer patients. When one is confronted with the fear of death and with the reality of one's health betraying them, inevitably people feel alone and isolated from the world (Kuhl, 2002). The impact of isolation for northerners is exacerbated due to the northern reality of lack of services, often geographically great distances from families, and smaller population bases to rely upon for support. It would be a somewhat obvious conclusion to draw that the service helped to ease isolation; yet, I was surprised by this theme, whereas other themes which emerged I had anticipated. In order to make the data, the research, and this study meaningful, I was compelled to dig deeper into this unexpected theme.

Throughout this study, I have mentioned that the service provision has been provided by myself to the people in the north. I worked with over 500 patients and families through Telehealth. I have been the only person providing this service and I have no other similar co-workers to draw upon for support or guidance. In essence, I have been isolated within in my practice. This practice isolation may be so inherently part of the work that it is difficult to

articulate, acknowledge, and even make connections with how important easing isolation is to both myself and my clients. I am obliged to explore how easing isolation is important and how this is connected because without a further exploration, my study may lack an important element of meaning. Some following statements may be relevant to this understanding. People in northern Canada innately feel isolated from other people for the simple reason of geographic differences. People in northern Canada can feel powerless and isolated due to decisions being made about their lives from the south (Zapf, 2012). People experiencing cancer feel isolated from their peers and support people. People experiencing grief and loss feel isolated and disconnected. Almost all people dealing with cancer experience grief and loss.

This last explanation fundamentally rings true for me in a way that can fit and join the three other explanations together. The work which involves Telehealth creates a geographic isolation factor for the worker providing the service. Additionally, this type of work as a specialty and within the context of its provision isolates the social worker, myself, from other co-workers as their duties and responsibilities are vastly different on multiple levels but on the simple and obvious level: the Telehealth aspect. Finally, as a social worker connecting often periodically for years with people on intimate matters that are often heart wrenching and tragic, I experience grief and loss. This is very common for oncology social workers. As Joubert, Hockingralph, and Hampson (2013) point out

> Social work in oncology presents a unique challenge. The direct practice work with patients and their families is frequently both physically and emotionally taxing and, despite our best efforts, the work does not make cancer go away. As families require

ongoing intervention and consultation, social workers build long-term relationships with clients, many of whom will die. (p.6).

This grief and loss is well documented in the literature and is often called vicarious trauma or compassion fatigue or burn out. (Cashevelly et al., 2008; Rohen, 2005; Simon et al., 2007; Werner–Lin & Biank, 2006). I view it as something slightly different from any of these terms. Grief and loss occurs for me within this context of delivery not because of the trauma of being witness to the tragic stories and not because of the experiencing too much loss due to the nature of the work but because of the isolation of the work (being separated from the patients and the other members of the team – geographic isolation); the lack of peer support from other social workers (professional isolation) ; and finally, the inability to create policies and practices which would minimize the grief and loss aspects of the work (political isolation). These three isolation aspects, which I believe increase and intensify grief and loss, are not different from those mentioned by the participants or within the case examples. Alice was experiencing grief and loss yet the system in place to assist her increased her feelings of isolation by recommending an antidepressant which would take away her raison d'etre. Arguably this could be categorized as a political isolation aspect because the policy and practices are not reflective of the needs and realities of the users of the service. Participant Bob highlighted his isolation from his peers and thus support in his statement "I didn't tell anybody ...., not even the guys on my crew and stuff like that". With the case example of Jo, he was angry because he could not return home due to his deteriorating health condition which required him to stay in a wheel chair. As well, he had argued that his medical treatment was inadequate. From my practice experience as well as my real lived experience as a northerner, this is not an uncommon feeling. Residents of northern Canada often perceive that if they lived in the south, services would be more abundant. If one looks back

at Jo through the eyes of a man experiencing grief and loss, one can then see how geographic and political isolation intensify these feelings.

I believe that future social workers who may provide Telehealth service to people living in the North need to be prepared for isolation: geographic, political, and professional. As well, social workers need to understand that their isolation is quite similar yet exponentially less distressing than the isolation experienced by their clients with cancer. Furthermore, grief and loss exacerbated by isolation is an essential component of the social work practice for both the client and the social worker.

Structural Analysis

One of the purposes of this study was to provide some information to future social workers working with Telehealth to northern population bases and more specifically to northern BC. The data demonstrates that the structural reality of living in the north impacts or influences service provision. I believe that social workers then need to incorporate this into their practice. The challenge however is adding the element of Telehealth to the mode of service delivery. If someone was to ask me in the future, "What would you recommend doing when providing psychosocial care to cancer patients via Telehealth?", I believe it would be difficult to break down the information into doing, or the practical elements of social work without including the understanding, or the theory of northern social work. This understanding or theory of practice is better understood one when looks at the position in a structural analytical way. Firstly, it is gained through examining the structural set up of the supervision component with the position and the structural setting of the position. Secondly, it is enriched by a structural social work analysis.

Supervision and Structural Setting

As mentioned previously, my position was formed out of the Northern Cancer Control Strategy (NCCS). My position, which I resigned from in November 2013, was based in Prince George, which many would likely argue is considered to be south in comparison to the rest of Northern Health which is seen as north and rural. The structural setting of this position was formulated to provide psychosocial oncology services to all cancer patients receiving treatment from their local cancer clinic (appendix B). I was the person hired into the position in January 2009.

Interestingly, the supervisor of this position was the head of the social work department at the University Hospital of Northern BC (formerly known as Prince George Regional Hospital). Social work supervision is extremely valuable to the supervisee but also to the maintenance of high quality practice and program delivery.

> The aim of professional supervision is to provide an on-going opportunity to for critical reflection and learning that takes into account the political, organizational, professional, and practical, administration and cultural contexts of practice. Consideration of the emotional impact upon the social worker is integral to this process of critical reflection. (Beddoe & Egan, 2009, p. 410).

The structural setting of this position was placed under the management and direction of a person who is only responsible for services within Prince George; therefore, there was a fundamental gap in understanding of the unique differences and challenges each community faces outside the Prince George area. This gap contributed to incongruence between the social work practice to the communities in the north and how as a worker, I needed to be

cognizant of that and adapt service for it. Additionally, the supervision was provided by someone who was not an oncology social worker.

> Social work supervision has a focus on both short-term (educational supervision, promoting effective social work practice and supporting the social worker to feel about doing the work), which aligns with the long-term—and critical—objective of providing clients with the most effective and efficient service that the agency is mandated to offer. (Kadushin & Harkness, 2002).

The specialty of providing psychosocial cancer care to northern residents was not under the umbrella of the experts for BC in this field: the Patient and Family Counseling (PFC) Department for the British Columbia Cancer Agency (BCCA). This caused me to have both internal and external system conflict. The internal system conflict arose when recognizing that added knowledge and direction in terms of increasing competency was needed but there was no person within the system to address this need. The external system conflict arose when recognizing that some policies and procedures from the experts did not meet the needs of northern BC cancer patients and families. For example, in searching for clinical consultation from my supervisor or other co–workers about psychosocial care for the case example of Alice, I likely would be told that the patient would need to engage with their mental health counselor in their home community. This would be based on the reasoning that within the hospital system in Prince George, social workers do not address mental health issues in a clinical manner; they refer to the mental health system. An example of how the external system would cause angst is how as a Northern Health worker, I felt powerless to address how the policy of PFC BCCA of referring to home community to address psychosocial issues lacked awareness of the resources with home communities. For

example, for those few hospitals in Northern Health which have social workers, all have discharge planning to in–patients as their priority and dealing with psychosocial issues and practical matters of an outpatient cancer clinic is not a focus of attention. This policy also does not address what a patient is to do if there are no home based services. Often as the sole based cancer care social worker for Northern Health, I was conflicted in how to achieve the best service level for cancer patients and their families.

Structural Social Work Analysis

It would be lacking to attempt to provide meaning and guidance for future social workers wishing to provide Telehealth service for oncology patients in the north without discussing the aspect of this position within its context and system. In order to achieve this, I use structural social work theory. Structural social work practitioners who work within a system, or in this study a health care setting, I believe need to follow the principles of practice of *interpersonal work* and *personal is political.* According to structural social work theory *interpersonal work* is important and "it must not de-contextualize human activity or treat it as a de-socialized or a historical way" (Mullaly, 2007, p. 292). This recognizes that both the client and the provider interact with each other and have a real impact on the interaction. Future social workers coming into this position should try to be aware of this and perhaps the previously highlighted points in the discussion about isolation, grief and loss, and northern realities will provide a guide.

Personal is political within structural social work practice always makes the link between the personal problems and the structural causes for them. Individuals and their families who face cancer and need life sustaining treatment are often dependent upon a

system, a health care setting, which can be structurally oppressive. With regards to the northern health psychosocial oncology position, one individual was put into place to be available to provide service to potentially thousands of people. The structure was set up to provide service delivery to individuals with cancer via Telehealth. The British Columbia Cancer Agency predicted that almost 1400 people living in the Northern Health Authority were diagnosed with cancer in 2013 (BCCA, 2013). Structural social work examines the ways in which structures in society perpetuate oppression and inequality. The theme of inopportune timing demonstrated that the service was not always available for the participants. Participant Jenny commented that in order to improve access to service

> You do realize though, you will have to clone yourself. (laughter) You will not be allowed to take holidays or have days off, and you will have to be available for us 24 / 7 .

"Structural inequality is a somewhat abstract, technical, bourgeois and polite term that covers up its violent outcomes. We should call it what it is – socially sanctioned structural violence" (Mullaly, 2007 p.276). I believe that my former position, which albeit does provide some services to some people, perpetuates oppression and inequality and more so, it condones it. This is due to the obvious – how is one person able to provide quality service to potentially thousands in need? How then is it not structural violence when people who require the service do not receive it?

Northern Health and the Northern Cancer Control Strategy sanctioned structural inequality by putting in a structural setting for a position into place for delivery of service via Telehealth, yet it did not provide evidence-based training on how to implement the service.

Further, it placed this position under the management and guidance of a supervisor with little to no responsibility or knowledge of the complexity of northern realities. Finally, there was no formalized evaluation on how the patients perceived this method of delivery nor on how the health care providers in the community cancer clinics saw benefit to the service. How does one truly wish to meet the needs to the users of service when they don't ask them about the service? This gap led to this research study as I believe as a social worker it is my professional responsibility to not only follow evidence based practice or emerging body of knowledge but also aid to the body of knowledge through research and evaluation.

Chapter Six: Limitations and Recommendations

Gaps in Data

Costs

A gap in the data from the participants is the notion of costs: whether the costs savings to using the service or the financial burden of cancer treatment in general. I expected that all the participants would discuss finances in the interviews, and this was demonstrated in my statement:

> I think a lot of patients are going to say my understanding is that social workers helped with financial um services. Especially the participants who might come from the northeast, just because if they come from the northeast and have gone to Alberta, that's all their social workers do is um help with financial services. They don't help with anything else so I think that's what patients will say.

I was surprised by the lack of discussion around finances because unfortunately, all too often the financial implications for cancer patients are life altering. The Canadian Cancer Society (2013) states

> Nine out of ten Canadian families touched by cancer report some form of financial challenge as incomes decline and household costs rise. For some, a cancer diagnosis begins a financial tailspin that pushes ordinary people over the edge resulting in debt, distress, bankruptcy and even a lifetime on social assistance.

Only two of the seven participants mentioned that costs of cancer were a financial hardship to them. Interestingly, in a study by Shepherd et al. (2006) the financial savings to cancer patients in rural and remote locations of Australia receiving tele-psychology service was a

major benefit to the participants. Similar findings exist in other studies. Stalfors, Bjorjolt, and Westin (2005) examine costs to the health care system and patient to implement and use Telehealth equipment for health care versus face to face care: "The direct non-medical costs i.e. costs for travel, were higher in the face-to-face group compared with the telemedicine group" (Stalfors et al., 2005, p.207). The direct medical costs would be significantly lower once the telemedicine equipment costs are absorbed and not part of the startup. Therefore for both the non-medical costs and medical costs, telemedicine is a more cost effective way of delivering health care to rural and remote patients. (Stalfors et al., 2005). In a study on utilizing Telehealth service in Northwestern Ontario, Sevean et al. (2008), identify that people who use Telehealth service value and highlight that this mode of medical service results in less financial burden to them. Perhaps in the future, if research looked at the financial implications specifically to northern BC residents in receiving cancer treatment both via Telehealth and through extended travel, participant answers may reflect that of previous research.

Psychosocial Information

Cancer and its impact on people living in the north was not an explicitly stated objective of the study; however, some discussion about cancer for northern residents would be expected especially regarding people experiencing cancer and their involvement with social work services. In fact, I anticipated that participants would likely speak about receiving psychosocial oncology services. In my own interview prior to the participants', I stated

> I think they're going to just perhaps they'll say grief and loss issues, sexuality issues, finance issues, understanding of cancer illness issues, advanced care planning issues, like any of the above. Anything that might come up for somebody that's experiencing cancer: body image issues, family dynamics, I think those are the sorts of things that I talk about with patients most often.....Finances, coping with a diagnosis, and like anxiety issues. Anxiety related to the diagnosis, anxiety related to sleep, anxiety related to the next coming up test. I think those would be the top three.

As a researcher and practitioner, I was hoping that participants would highlight the type of service received such as "we talked about my anxiety and fear of death." In this way, future social workers would be able to have a clearer idea of what issues northern residents of BC experience when dealing with cancer and thus be able to guide their learning and perhaps practice.

Unfortunately, participants did not speak of what the social worker, myself, did in terms of intervention. There could be a multitude of reasons for this; and I believe some exploration of this reasons are pertinent to helping address the two main questions of the study. *What was northern BC cancer patients' experience using Telehealth service from a social worker? 2) What do social workers need to know in order to provide social work service to cancer patients via Telehealth?*

One reason could be that the participants did not remember much of the specific details as it is quite common for people undergoing cancer treatment to have memory loss (Silverman & Davidson, 2009). Another reason could be that the participants did not wish to speak of specifics in great detail as it is often difficult and distressing to talk about issues

such as death and dying or loss of financial freedom or grief over control of one's own body. I believe though that it likely is a combination of the above mentioned reasons and mostly the following explanation.

I provided each of the participants in this study the social work services via Telehealth that they were questioned about. It may be possible that the participants did not feel the need to explicitly state what the interaction included as this information was mutual knowledge. As a novice researcher, I did not probe or ask questions of the participants about the specifics of psychosocial interaction and I did not recognize that the information was not stated within the interviews until much later in the research analysis process. I thought about reaching out to ask more information. Unfortunately, most of the participants are deceased and it would be insensitive to go back and ask those living partners. If in the future a similar study was to occur, it would be perhaps more advantageous to have a separate person conduct the study and not the social worker who delivers the service, as he or she may gleam more information regarding the content of the interaction. This option though is unlikely to occur for the same reasons of why I myself sought and studied the phenomenon. Northern and rural residents of Canada are often not included in mainstream research; and if the research is conducted it is either through a southern political metaphor or else completed by the person providing the service delivery.

Being an Ally Not a Southerner

Telehealth oncology social work service is centralized in its location yet the service is provided throughout the Northern Health region, to its Community Oncology Networks. As the Telehealth oncology social worker, I am not from the cancer patients' community and

could be viewed as an outsider. Outsiders entering into northern communities can encounter resistance and opposition. Sellick & Dellaney state (1996)

> Communities quite naturally then may resist 'outsiders' attempt to 'know' them because that knowledge, which is partial and so often vested with outside interests, violates their sense of who they are and limits their imagining of who they become. (p.42)

Given this, it would be likely to receive feedback from the interview participants that either the service should occur within the cancer patient's community or that the service was not responsive to the needs of the patient. In fact, I anticipated that on some level comments like this would be mentioned. I stated in my research bias interview, "I know that I'm often viewed as a southern person implementing southern regional policies into northern communities, or I could be perceived as that way." Although the participants did not overtly mention this within the interviews, there were a few comments that alluded to elements of opposition which was discussed earlier. Non-overt statements could be a reflection that the participants were not aware of their own subtle culture of opposition. It could have been a reflection that the participants did not want to disrupt the program in any way for fear of it being taken away and the community being left with nothing. It could have been due to feeling uneasy in expressing dissatisfaction with the service given the service provider, myself, was conducting the interview. Finally, it could have been due to the fact that I practice from a northern social work framework; a northern social work framework is one that acknowledges northern realities, and values and understands the importance of northern relationships. Thus, the participants may not find the need to bring the service to their community or they may not believe the service was unresponsive to their needs. Perhaps,

due to my own northern metaphoric way of being, I could be considered an ally not a southerner.

Methodology Limitations

As mentioned, my social work availability to communities could be seen as an imposition versus a welcome. This is perhaps reflected in earlier mentioned gatekeeping element of the Telehealth service. Thus although the study has attempted to provide some meaning to the lived experience of cancer patients using social work service via Telehealth in northern BC, it has only used data and work experience of those who have accessed the service versus those who have not. Questions which could be explored in future research would be "what are the barriers to utilizing oncology social work service in northern BC?" "How would you like to see psychosocial support offered to cancer patients in your community or to you in your community?

The study only interviewed five patients plus two partners who met the criteria: having experienced a cancer diagnosis within the last 48 months, having seen a social worker through Telehealth service, and living within the northern health authority. Perhaps if more people were interviewed, the sensation of the experiences would not be reflected as positive as it was. As well, maybe the people interviewed, choose to participate in the study because of their positive experiences and those that did not participate choose so because their experiences were more negative. People with a negative view point on the service may not have wished to participate in the study because the person conducting the study was myself and this could be difficult. They may have felt awkward to come forth and be interviewed even by another person which was an option in the study due to these difficult feelings or

opinions to express. As well, I believe that a potential participant may feel vulnerable providing negative feedback on a service which his or her health care provider recommended; especially if this health care provider may be responsible in the future for providing him or her life sustaining medical treatment. It may be interesting to repeat the study with participants who utilized the service without a recommendation or referral from their health care provider.

This study examined only those participants who accessed service through Telehealth; it did not focus on individuals who did not access as it was technology and not face –to –face service. "It has been suggested that as remote tele-care technologies are introduced more widely, some form of digital inequality will persist and it is possible that those who demand purely face to face interactions will receive a residual service" (Waltin & Rogers, 2012, p.111). Future work with regards to looking at people who use Telehealth versus those who choose not to may help to identify and modify services to meet the needs of all cancer patients in the north and not just those willing to use Telehealth.

Recommendations

The points outlined at the beginning of this chapter provide some direction and recommendations for future social workers wishing to provide a specialty in health care via Telehealth to a northern population. The first recommendation is that the social worker should be provided with some training on how to utilize Telehealth equipment while engaging in clinical interaction. The data analysis demonstrated that participants appeared to value or appreciate the service when it was simple to use, when the visual aspect of service

appeared somewhat like face to face, and when the interaction was friendly and relaxed. My experience concurs with the data obtained from the participants.

As mentioned in the discussion section, critical to the positive Telehealth experience is rapport building and this is achieved clinically in subtle different ways than within a face to face setting. The training in the use of Telehealth would include both the technology component and the clinical elements with an aim at rapport building. For the technical components, I would highlight that sometimes the actions that what we do that seem intuitively correct, are not. For example, with my experience, I realized that if a person had difficultly hearing me, it did not mean that I was to speak louder or lean into the television to get closer to it. Instead the person on the other end needed to turn up the volume on the television. I also learned that if I looked into the camera placed upon the top of the television screen, believing that I was focusing my attention on them, my clients' experience would be that I was not looking at them. My eyes would be focusing above their heads. I needed to look at the person on the television screen and not at the camera. These are small but critical technical aspects of Telehealth and should be part of training.

Once the technical elements of using the equipment are understood, training on the clinical components should occur. This training does not need to be extensive; but certain key pieces of information should be explained. For example, I have found that it is important to acknowledge the different interaction and talk about it. A simple statement like "people find this a little odd at first, but soon it becomes almost like face to face" is helpful. At the end of the session, acknowledge the distance through a simple gesture of a virtual hug or hand shake is nice. It can be useful to have a box of Kleenex in both the clinician and client's room. In this way, I have held up a box of Kleenex when someone is crying, and they then look for the

one within the room. It is also critical to be at ease with silence as the silence can seem more pronounced with Telehealth than in person. I learned not to fill in the silence with words too quickly. Finally, I found that it is essential to be relaxed and comfortable both with the technology and clinical interaction through Telehealth. The more this occurred for me, the more rewarding, meaningful and easy my interaction with cancer patients in Northern BC through Telehealth became. I believe that training should allow novice social workers the opportunity to witness more experienced clinicians engaging with clients in this way to help them become relaxed and comfortable. I strongly recommend training with the use of social work and Telehealth and believe that it can occur within the workplace or through the university setting.

The second and third recommendations are more so about the system or the structure of the position. The second recommendation focuses on supervision and the third recommendation highlights the importance of robust services. These recommendations, I believe will help future social workers understand the why of their position and advocate for it to be in line with the structural themes of the data.

According to Joubert, Hockingralph, and Hampson (2013), social work supervision is a key component to oncology social workers. Without an appropriate management and supervisory structure, these social workers are at greater risk for burnout and vicarious trauma. Critical components to reduce burnout and vicarious trauma include formal and informal supervision. The formal includes a supervisor who actively guides and consults with his or her worker and provides every opportunity to increase the worker's knowledge base; inherent in the guidance and direction is that the social work supervisor is a practitioner of oncology. The informal supervision is the ability to connect with peers on not only a

scheduled basis but on ad – hoc basis as well. I recommend that a system is in place in which supervision is provided by another social worker actively involved with cancer care.

It is not uncommon for social workers in northern settings to suffer from burnout (Brownlee, Delaney, & Tranter, 2002). I believe oncology social workers practicing in northern locations have a greater potential for vicarious trauma and burnout. They often work in isolation and are not part of a system in which they can connect with co-workers providing similar duties and in this setting of NHA, he or she is not supervised by a social work oncology practitioner. It is not possible to provide quality psychosocial oncology service to northern health residents by one person. I strongly recommend that more than one position and person provide this service. In addition, I recommend northern oncology social workers do not practice in isolation; instead they should have an empathetic robust team that works within the same scope of practice.

Chapter Seven: Conclusion

The experience of cancer patients living in northern BC who access Telehealth social work service may be difficult to fully understand in this study. However, there are important realities and meanings which exist for the participants and perhaps for others who have utilized the service. Participants and perhaps myself who happens to be the researcher, albeit difficult to admit, who deal with cancer in northern BC, feel alone. The participants received the service at inopportune times which could be reflective of the gatekeeping element of community professionals and the perceived notion that the service was from the south. Participants were unaware of the service and felt discomfort with it. However, once rapport was achieved through incorporating northern realities into the experience, participants felt the service was helpful and comfortable. Ways in which this occurred was through taking time to connect with the participants almost on a personal note. It was also important to keep the technology process simple, to incorporate regular one on one techniques such as showing diagrams in the process, and to provide useful practical information. The Telehealth method of delivery provided them access to a service which without it they may not have had such a service due to their geographic location. Despite the positive elements found with using Telehealth and oncology social work to northern residents, careful consideration should be made before this mode of delivery is more widely used.

> While the rhetoric around Telehealth cites improved access for regions and for persons who are more marginal in their ability to access services under the current system, there needs to be a recognition that technological, administrative, and funding patterns may restrict (it)... despite the rhetoric of 'virtual health care'. (Kraetschmer et al., 2009, p. 662).

I would suggest that system and structural support be more thoroughly implemented in order to help achieve an experience in which the cancer patient in the north 'has a virtual cup of coffee' with the social worker from the south.

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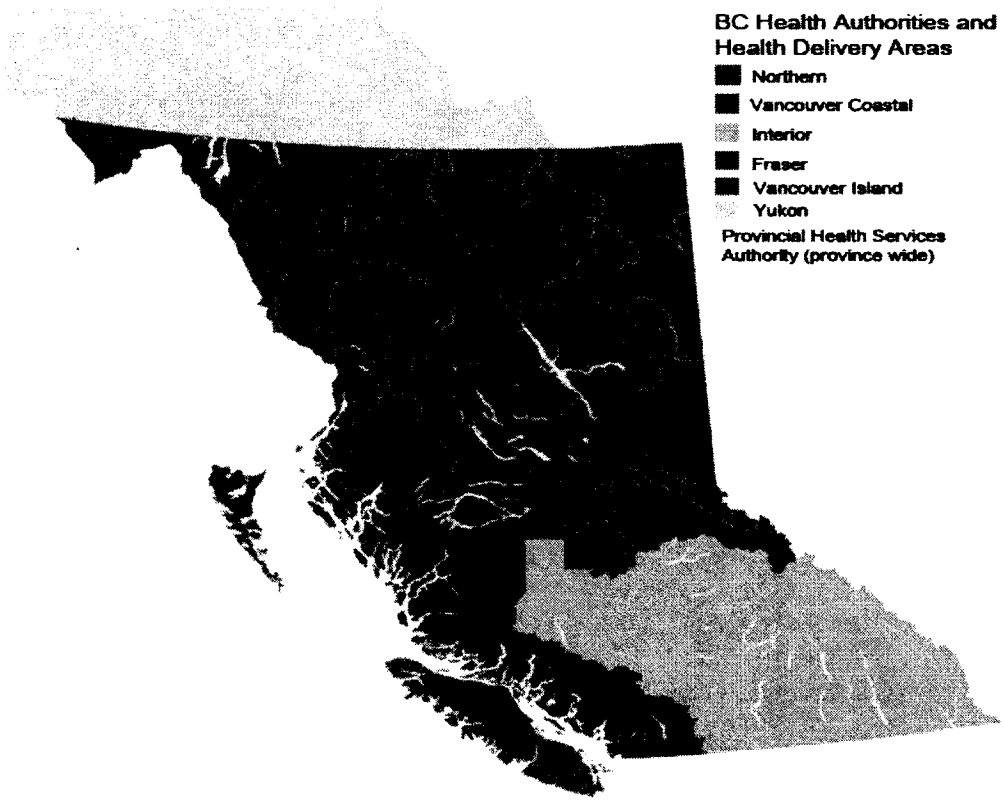
Appendix A – Health Authority Areas



Map of British Columbia. The area in blue depicts the Northern Health Authority

Appendix B – Northern Health Community Oncology Networks

This is a picture of the Northern Health Authority. It demonstrates the areas that have Community Oncology Networks.

Appendix C - Interview Questions

Evaluating Cancer Patients Experience of Telehealth

Social Work Intervention

Thank-you for agreeing to participate in this interview. You have been chosen because within the last year, you spoke with a cancer care social worker via Telehealth Service. The purpose of this interview is to gain feedback of the use of Telehealth service with social work intervention. The information will be used for the purpose of gaining insight into ways in which social work service can be used with Telehealth for cancer patients living in Northern British Columbia. It will be valuable in guiding future social work service and practice for cancer patients. No identifying information of the participants will be revealed.

1. Were you aware of cancer care social work service prior to meeting with him/her via Telehealth? (If yes, answer question 2 do not answer 3. If no, go to question 3.)

Yes No

2. Please describe your prior understanding of this service.

_____

_____

3. Please describe what you thought the social work service would be like before using it.

_____

_____

4. How did you learn of cancer social worker service availability through Telehealth?

_____

_____

5. Please describe your Telehealth experience.

_____

_____

6.Please describe the interaction with the social worker thru Telehealth.

_____

_____

7. Please describe your impression of social work service using Telehealth.

_____

_____

8. What would you tell other cancer patients about if they were to use social work service via Telehealth?

_____

_____

9. What would you tell other cancer care social workers if they were to use Telehealth with patients in the future?

_____

_____

10. Please comment on anything else that you believe is important about your experience with cancer care social worker and Telehealth.

_____

_____